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ABSTRACT

The participatory research model used by the Rehabilitation Research and Training Center at the University of Wisconsin-Stout is discussed, with a focus on the value added to the research process and relevance of research applications when research is rehabilitation-need based and the research-to-applications process model is used. Information is included on: what makes the Center work setting unusual for participatory approaches, how the participatory model came about at the Center, the two components of the model, constituencies and constituent involvement, relevance and involvement in the stages of research-to-applications, three examples from the Center's use of the model, guidance for making participatory models work, and some of the promises and potential pitfalls of participatory models. The three examples of the model's use involve community-based rehabilitation needs of American Indians residing on reservations, development of a vocational assessment protocol for use with persons with traumatic brain injuries, and development of a state rehabilitation plan for Ohio. (Contains 16 references.) (SW)

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Constituents Make the Difference: Improving the Value of Rehabilitation Research

Fredrick E. Menz, Ph.D.

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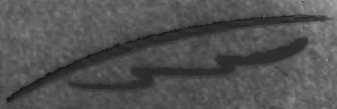

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University of Wisconsin-Stout • Menomonie, Wisconsin

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Fredrick E. Menz, Ph.D.

Rehabilitation Research and Training Center
on Improving Community-Based Rehabilitation Programs
University of Wisconsin-Stout • Menomonie, Wisconsin

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I. Preface

This book discusses the participatory research model used by the Rehabilitation Research and Training Center at the University of Wisconsin-Stout. The goal of this document is to elaborate on the value added to the research process and relevance of research applications when research is rehabilitation-need based and the research-to-applications process model is used. The succeeding chapters cover the following: (a) What makes the Center work setting unusual for participatory approaches; (b) how the participatory model came about at the Center; (c) the two components of the model; (d) constituencies and constituent involvement; (d) relevance and involvement in the stages of research-to-applications; (e) three examples from Center's use of the model; (f) guidance for making participatory models work; and (g) finally, a discussion of some of the promises and potential pitfalls of participatory models from the author's experience.

While I presumed to write this book, I cannot take credit for it. This is a product of the experience, expertise, and developments of the Center's colleagues and constituents. As you will find, the model we subscribe to is a product of our past, built upon the labors and involvement of staff and constituents in research and applications, and a map for getting into the future. Talk to any of us today and tomorrow and you will find we have taken another step along the course of constituent-driven research. This model provides us (and perhaps you) with a foundation from which to grow, better research and most importantly, more useful answers to the issues surrounding disabilities.

Fredrick E. Menz, Ph.D.
July, 1995

II. How the Center's Participatory Research Model Came About

The model for participatory research discussed in this book was designed not only to be applicable to discrete research projects but to be applicable in guiding our entire program of research and training efforts. The context referred to for such a program of activities is defined by the broad mission that our Research and Training Center has had over the past 20 years in rehabilitation and the specific priorities identified by the National Institute on Disability and Rehabilitation Research for each 5-year funding cycle. A participatory model designed under this context must be efficient (significant resources are used to maintain it) and work throughout a total, evolving research-to-applications plan that includes multiple interrelated studies, training, technical assistance, and other activities all of which are geared toward achieving certain specified goals.

Rehabilitation Research and Training Centers as a Programmatic Context for Participatory Research

Rehabilitation Research and Training Centers are funded by the National Institute on Disability and Rehabilitation Research under provisions of the Rehabilitation Act of 1973, as amended in 1992. Nationally there are 46 mission-directed centers charged with conducting programmatic research on problems of long-term significance in the rehabilitation of individuals with disabilities. Each Center is funded on a 5-year cycle, with many of them conducting programs of research that have been ongoing for as long as 30 years. The Centers are the National Institute's long-term research program, and nearly half of its budget goes toward maintaining this network of Centers. Research programs at Centers focus on a thematic area of need, with priorities established for each 5-year cycle, and an open competition held to solicit the best programmatic approaches. The thematic areas at each Center represent long-standing problems in disability and in rehabilitation. Center programs engage high quality staff in research, development, training, and technical assistance activities to achieve solutions to all or parts of problems related to the Center's theme area. The areas include disability issues in vocational rehabilitation, psychosocial rehabilitation, medical rehabilitation; such age groups as children, youth, adults, minorities, and aging persons; and such settings as hospitals, rehabilitation facilities, independent living centers, urban and rural delivery settings, state and community systems, and various cultural environments.

The Rehabilitation Research and Training Center at the University of

Wisconsin-Stout is working toward solutions to problems in the vocational rehabilitation of individuals with severe disabilities. More particularly, the Center's mission is directed at improving rehabilitation practices that take place in local communities and through community-based organizations. Over the past six years, the Center has been conducting research that impacts on the productive and social lives of individuals with either traumatic brain injury or psychiatric disabilities, though not exclusively. The Center has a very applied orientation and the program of research deals with evaluation and development of community-based rehabilitation programs and practices that improve the economic status (i.e., jobs, income) and social integration (i.e., community participation, housing, acceptance) of individuals and family members with needs for rehabilitation that are the consequences of disability. This program includes studies and projects that span consumer, practice, and policy issues: For example, the activities range from finding ways to influence policy and legislation, to document alternative program models; to identify benefits for consumers; to define needs and design new practices and techniques; to develop instrumentation and treatments that directly improve rehabilitation outcomes; and to produce books and various training materials that can be used by practitioners, administrators, and individuals.

Coming of Age in Participatory Research:
We Didn't Know We Were Doing That

For over two decades, the Center has been committed to the inclusion of persons with disabilities and organizations concerned with improving rehabilitation practices in all of its research and training activities. For the first 15 years, that involvement occurred because the individuals and organizations who had the most to offer to make our work possible and could help us remain relevant had those characteristics. It was not until the late 1980s that the Center began to formally examine how research and training were being conducted and how the Center might improve its linking of research and rehabilitation applications. Three major events led to formalizing the research-to-applications model discussed in this book.

Resource Limits and Need for Impact. The first of these events occurred in the late 1980s when the Center redefined how its research and development efforts would be linked to training and other forms of dissemination. Rising productivity in research and rising costs to provide many training programs around the country began to outstrip Center resources to support those activities. Consumer-constituent committees were formed by the Center to help change how we did the applications part of the Research and Training mission. The

committees included service consumers, family members, disability advocates, state and local program administrators, national leaders, employers, and educators and typically met at the beginning of the research cycle and at the conclusion of specific research studies.

These committees were formed to complete three types of activities for the Center's research and training program: (a) Identify priority research issues (a traditional role), (b) describe potential products or media that the research might also be directed at developing (a new factor to consider in research design), and (c) identify optimum formats for translating research into applications in rehabilitation practice (at the conclusion of the research). While the first of these activities is a traditional function of an advisory committee, the other two activities significantly changed how research and applications were linked. The identification of potential products up front caused research planning to be directed toward applications. Bringing potential users together to define specific products at the conclusion of the research reinforced, for the Center, a clear expectation that applications in rehabilitation would be required.

Modeling for Program Improvement. The second event that prompted the Center to formalize its research model came about when the Center was asked to provide guidance to a regional Study Group to design "an approach to needs assessment that state rehabilitation agencies could use to prepare their state plans." The study group consisted of program planning, evaluation, and policy staff from state rehabilitation agencies in Region V and the Center.

The Group became more conceptual than state directors expected, recognizing from the onset that there would be no single assessment approach that would work for every state and that there were already numerous texts available on virtually every assessment approach, though not necessarily familiar to staff in rehabilitation. What was also apparent to the Group was that there was no clear assurance that a needs assessment (or any research, for that matter) would actually be used to define and design programs (or be applied). As a result, the Study Group "put needs assessment into socio-political context of rehabilitation policy development" and conceived an assessment-planning-development-evaluation model.[1] The central concept in that model is the

[1] Region V includes Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin. The product of the Group was a two-volume publication. The model is presented as a process for conducting dynamic planning in the first volume. The second volume is a companion reference that linked some of the specific methods and available resources to the requirements outlined in the Rehabilitation Act amendments for state plan development.

requirement for involvement and inclusion of "relevant stakeholders" in all phases of assessment, planning, and evaluation.

> Stakeholders are people and organizations likely to be affected by or affect any potential change. They include proponents and opponents to change. They have vested interests in what the agency does or can do and are found both inside and outside the agency. Stakeholders can be a vital resource at all points in the assessment and planning: for ideas about how and where to get data, in instrument development, in collecting data, and in interpreting and developing implementable change. (Region V Study Group, 1991, p. 74)

The principles proposed by the Study Group were clearly applicable to the Center's efforts to make its research have a higher applications yield. Clearly, the model was articulating some of the Center's nascent actions to make more effective use of consumer involvement in research and to achieve change and innovation in rehabilitation practice as outcomes of research. The Group went on to conclude that needs assessment (or, in our case, research based upon priority needs) must be founded upon six principles:

1. Expectation during all phases that research findings will be used in decision making;

2. Planning for utilization begins at the onset of the study;

3. Recognition that neither the research nor its recommendations are conducted or used in isolation from other activities, priorities, or sources of input-guidance available to those who make use of the research;

4. Need to include important change agents throughout the research;

5. Careful application of quality control throughout all the needs assessment and planning to ensure credibility for the research; and

6. Recognition of the importance of accommodation in linkages among the research, decision making, and change.

Commitment to Consumer Self-Determination. The third event really was an accumulation of the continuing involvements by Center staff in the movement to increase "consumer choice." Beginning as far back as 1975, the Institute on

Rehabilitation Issues[2] took up the issue of consumer choice and the rights of consumers as topics relevant to many aspects of rehabilitation (IRI, 1975; 1987; 1988; 1992). Successive documents went from discussing how consumers might participate to how to direct and control the course and consequences of their disabilities. Terminology improvements, alternatives to current practices, and, most importantly, changes in how the relationship of the individual with a disability and rehabilitation resources should be viewed came about through those documents.

It took little impetus for the Center to translate those proposed expectations for consumer involvement in rehabilitation practice to a Center expectation that research needed to be not only more valuable to rehabilitation practice but more directly valuable to individual consumers. It was not hard to imagine benefits from involving the potential users and beneficiaries of research at intermediate points in the process. Staff could, of course, see myriad problems for how we were currently doing specific research projects. However, the Center had considerable experience with having a lot of scrutiny from outsiders (i.e., constituents) all along and staff were regularly having to "sell the idea" to each participating research site and every group we trained.

In 1989, William Graves (1991), Director of the National Institute on Disability and Rehabilitation Research, placed before Centers the challenge that rehabilitation research is not sufficiently relevant to the needs of individuals with disabilities because (a) the dominant research model excludes subjective input of consumers and (b) is not action oriented. That challenge stimulated much of the behavior changes (in how we were doing research and training) to move more rapidly in the direction of greater participation of constituents. In 1991, we deliberately re-examined our research-to-applications approach and began to be more systematic in how we could more fully involve constituents in our approaches.

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[2] The Institutes are an annual process jointly funded by the National Institute on Disability and Rehabilitation Research and the Rehabilitation Services Administration. The Institutes were established nearly 40 years ago to produce training documents relevant to rehabilitation practitioner skill and knowledge needs. Each year study groups comprised of rehabilitation practitioners, rehabilitation administrators, and people who use rehabilitation services and who have special knowledge and interest in one of three priority topics work together over the year to develop separate documents for the three topics. The topics are identified by the Rehabilitation Services Administration, the National Institute on Disability and Rehabilitation Research, and the Council of State Administrators of Vocational Rehabilitation. Working for free, the 10-12 individuals who make up each group elaborate on the topics, do the needed research to acquire information, and write a 150-page document that is then nationally reviewed, critiqued, and revised. These documents have high utilization in rehabilitation preservice and continuing education and often predate issues in rehabilitation before they become priorities.

As part of an Institute on Rehabilitation Issues Study Group (this one convened by the University of Arkansas), we had the opportunity to envision and share on paper and in forums how we were seeing the relationship between research and development and the active involvement of the "key players" in changing and improving rehabilitation service delivery by their involvement and application of research (IRI, 1992). In that work and through our Center's staff development efforts, we began to document and strengthen practices that were being applied in the Center's program but were generally unsystematized. The drafts of parts of that Study Group report were used to influence the enabling tone of a Constituency-Oriented Research and Dissemination (Fenton, Batavia, & Roody, 1993) policy.

The approach or model presented in the remainder of this text derives from those events and is drawn from several previously unpublished analyses. The model will continue to evolve as we apply it with a greater variety of projects. Its value in the practice of research will be known as we more carefully track the benefits, problems, and solutions that we encounter as we gain more experience with it. Both the benefits and problems do need to be better understood and weighed if this type of approach is to be appropriately exploited in applications research. As described in the following chapters, the model is applied by a Center with multiple projects coordinated around a common mission.

III. The Participatory Research Model

Overview of the Model's Components

The model is comprised of two components, largely for organizational purposes in keeping with the dual functions of Research and Training Centers: Research and Development; Knowledge Transfer and Research Applications.[3] The Research and Development Component described later in this chapter applies a "rehabilitation need and constituency driven" process for selecting and planning activities specifically identified by the Center's National Advisory Council and expanded upon in staff analysis of current knowledge in priority areas. It aids the research program to retain sensitivity to changing social and rehabilitation needs and helps the Center anticipate potential applications of research to resolving practical rehabilitation problems. The use of a participatory research methodology helps us to keep the entire scope of activities relevant.

The participatory research methodology contributes to research relevance, helping the Center meet the mandates of the Rehabilitation Act to conduct a coordinated and advanced program of rehabilitation research that (a) is based on issues of significance to individuals with disabilities, including individuals with disabilities who are from diverse minority backgrounds, and (b) provides new knowledge and applications that consumers and practitioners can use to advance and improve community-based rehabilitation. The Center's research planning is based upon the expectation that greater impact from research and training can be achieved when critical input is obtained from significant advisory sources at all key points in the research-to-application cycle. Selected sources of input are tapped because of the perspective, the depth of knowledge, and the experience they provide. This input helps sensitize staff to important perspectives on research issues, rehabilitation problems, and ways to better achieve research goals and the application of the research.

This Center has introduced a general program plan for "rehabilitation needs and constituency driven research" that utilizes a constituency involving or participatory research methodology. This methodology is defined as

> a systematic approach to increasing the direct and indirect applicability of rehabilitation research. It is a methodology which is used in conjunction with accepted scientific research technologies. It can be used in research intended to acquire new knowledge, to establish

[3] This discussion was drawn from the April 1994 Continuation Application for the Center.

> principles for rehabilitation practice, to form theory in rehabilitation, to develop new solutions, and to create and improve the technology, devices, and practices used by individuals with disabilities and rehabilitation practitioners. It may be applied to solving practical, day-to-day problems of disability, as well as to theoretically promising research problems. [The approach] *has three central components: (a) maximum involvement of consumers and those constituents to be affected by or to benefit from research, (b) systematic actions which result from the research to achieve change or applications, and (c) the dynamic interaction of consumers and constituents in all phases of the research and intended applications of the research.* (Research and Training Center, 1992, p. 2)

Constituency Driven Research

Constituent is an intentionally broad term for all those directly and indirectly affected by the disability issues focused upon in the research: ***Constituencies*** *are people and organizations that have a perspective about what needs to be accomplished in rehabilitation, through sound rehabilitation research.* For the Center, this means that constituency includes individuals who represent and convey perspectives, feelings, attitudes, and needs of others within the constituent group.

In order for a constituency to be effective in improving research, the constituency must be able to convey (not necessarily speak about) the sentiment and significance of what is important and vital to the individuals whom they represent. Constituencies of the Center include consumers, practitioners, community-based programs, service delivery staff, agency people contracting for services, rehabilitation professionals, educators and trainers, employers, public policy leaders, advocates, family members, and others intimate with the issues and problems created by disability. Each of these constituencies can provide a distinct perspective or vision and provide enhancement to our understanding of the problems and the applications of research.

Beneficiaries *then are individuals, organizations, and/or processes that will make use of research findings.* While much has been written that the "ultimate beneficiary is the consumer," not all research will have direct, immediate, or knowable consequences on a specific consumer. A "hierarchy of beneficiaries" might be constructed, but doing so would not be worthwhile as such a hierarchy would falsely imply relative importance. What is important is being able to anticipate for whom direct and indirect benefits the research will accrue. In some research, an individual with a disability will be the most directly affected

beneficiary of a new practice or strategy. For some research, it may be the program or service providers who most immediately benefit. For some vocational research, the primary beneficiary may be those other researchers who are conducting research that contributes to our collective "base of knowledge."

Full Involvement of Constituencies in Center Program

Significant input is sought from two major sources for ideas, perspectives, guidance, and direction for the research and training program. The Center has a long-standing **National Advisory Council** that provides broad programmatic and policy guidance to the Center pursuant to its responsibilities in rehabilitation research, in rehabilitation training, and in rehabilitation leadership. The Council is comprised of consumers, family members, practitioners, advocates, rehabilitation providers, government and agency personnel, and educators. The individuals represent diverse perspectives, including those of primary service users and providers and individuals from minority and underrepresented populations. The Council continues to establish broad policies and serve as the primary external evaluation source to gauge the accomplishments of the Center under its mission and the priorities set forth for the Center in each funding cycle.

The second source comprises **Constituency Advisory Committees** that are established for the several studies. These Committees represent the perspectives of the major beneficiaries of specific research and development activities. When forming the total Center program, a single committee was formed to clarify critical issues of need for research and development and to plan research and training activities related to Federal priorities. Separate Committees and individuals now participate with the implemented research studies. They provide advice, guidance, and direction in each study. They assist the research staff to remain sensitive and responsive to the perspectives of the beneficiaries of rehabilitation throughout research and development.

The staff rely on both their Committees and the National Advisory Council throughout the study period. The Committees, as a whole, and the National Advisory Council meet once annually during the first quarter of the Center's fiscal year to review overall progress and changes in several studies and to recommend new research and training needs. The Advisory Council engages in evaluations of progress and quality of Center performance, while the Committees review needs for changes in research and/or training activities. Throughout the year, the Committees work directly with staff and the studies. Individual roles vary between studies and serve different functions with the study staff at different stages. Under some studies, quite different constituent committees may be

employed in different stages of the study.

Center's Participatory Research Methodology

Constituency Advisory Committees include individuals who are able to share their expertise and perspective, and who become integral parts of the studies. Relevant perspectives (e.g., concerns of persons from minority groups) about rehabilitation provided at the community level are represented among these individual constituencies. Studies are all developed around six stages: Identify and Prioritize Issues, Design Research Plan, Collect Research Data, Analyze and Report, Synthesize and Disseminate, and Transfer and Apply.

Figure 1 depicts the six stages in the participatory research methodology. That figure (and discussion in Chapter V) attempts to relate how the six stages of "idea-formation-to-research application" take place and how a high degree of constituent influence is obtained not only at the beginning and end of the research but throughout every stage of the entire research and development effort.

The six-stage process requires high interaction between constituencies and Center staff. The key element running throughout this type of conceptualization of the research process is that of "ownership and commitment to act." For the constituents, a thorough understanding of what took place and what the findings legitimately mean helps make them more critical and appropriate advocates for research because they more fully understand the results and research activities that went into obtaining the results. For the researchers, this "ownership and commitment" makes use of their greatest skills in constructive (i.e., practical) analysis and "cautious conclusion drawing."

Selection of Research Issues. Constituency representatives are sought to provide guidance and help identify critical issues in community-based rehabilitation. The studies and activities identified in the program are developed from their input, the announced priorities, background materials from the Center's accomplishments and findings, and the key issues they identified as priorities.

Planning. Once they identify priorities, staff prepare one- to two-page research prospectuses to solicit five types of reactions: (a) whether the idea should be pursued as a research or development activity, (b) their evaluation of priority(ies) the proposed activity should address, (c) whether grant or other resources should be sought for the study, (d) their suggestions for improvement, and (e) willingness to continue to be involved with the activity.

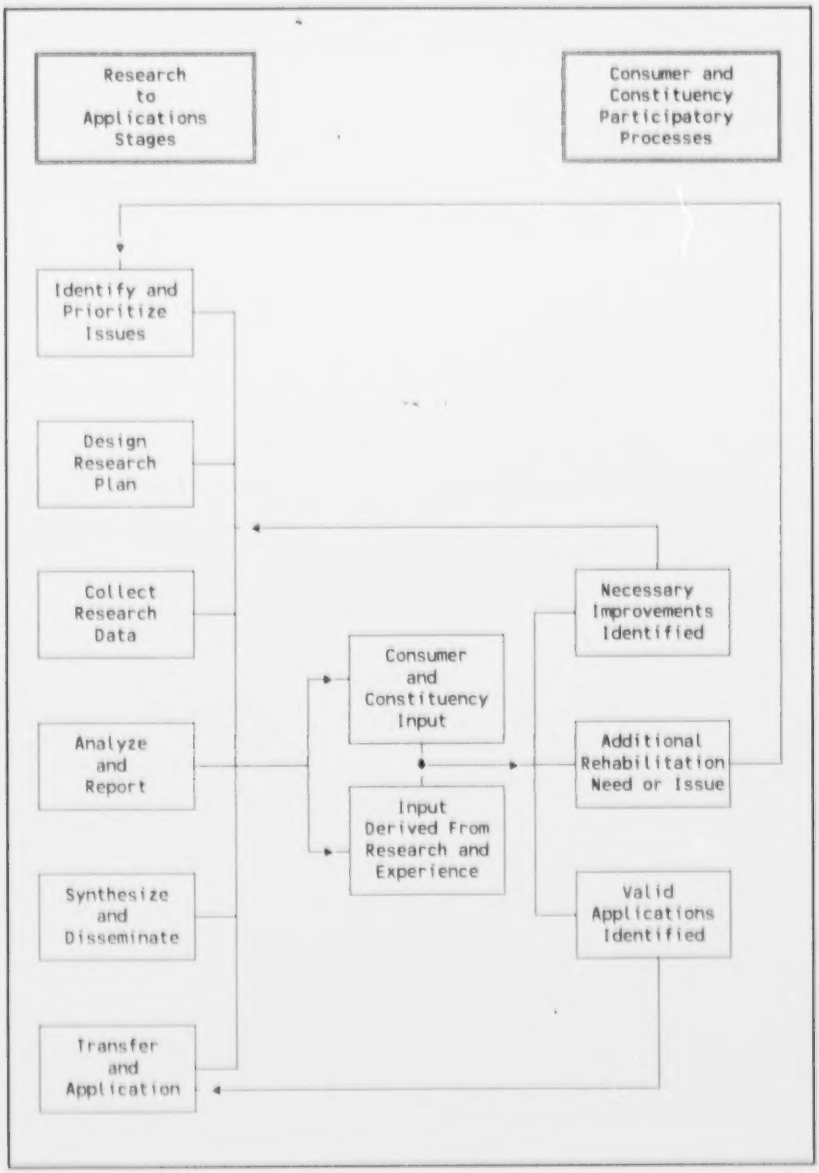

Figure 1. Participatory Research Methodology

Ideas considered most important are developed into research plans. These research plans are reviewed internally for scientific merit, relevance and sensitivity to the Center's mission, and for potential human subject protection issues. Decision making then determines whether to assign Center resources to it or to find additional funding resources. This sometimes includes reassigning existing staff or recruiting new staff, establishing other Constituency Advisory Committees, and/or preparing proposals to acquire the needed resources (e.g., field-initiated research, research and development competitions through the Office of Special Education and Rehabilitative Services).

Involvement Throughout Studies. Based on specific study needs and resources, the Committees meet at key points with staff (or by teleconferences) to review and influence the research. As suggested in the figure, modifications to the research plan and the shaping of potential products all come from the input and interaction between staff and the Committee members. Changes to an ongoing study can occur at any of the six stages. New research and development ideas (and new efforts for the Center) may be conceived at any of the stages. Innovations and practical applications may be conceived and executed as both constituencies and staff become better versed in the research-applications process.

Innovations and applications may also occur as constituent experience and validly crafted research results are combined. New information and the unique perspectives brought to the research-development effort by key constituencies (consumers, providers, family members, advocates) often lead staff to identify options, strategies, and devise applications which could never be otherwise accomplished. Advocacy and "face validity" of options and jointly devised strategies are important by-products and do much to promote adoption of research practices. These applications may have better value for our rehabilitation constituents and for rehabilitation practice than might occur were individual staff left to independently devise applications.

Doability and Quality Control. The methodology helps to increase the likelihood that each study will yield additive value and will be completed in a timely manner. First, each study's progress can be monitored based on completion of the six stages. Second, initial sites are identified for potential implementation. Third, the study plan includes preparation of a "concept paper" that allows full analysis of issues and needs for primary research before the study is fully initiated. Fourth, as interrelated studies are underway in the program, many constituents become invested in several studies and become "cost-effective experts" sharing their guidance and looking for applications in their areas of concern from across the several studies. Finally, this staging typically enhances

the sensitivity of the study as new information is continuously cycled through the Committee, as well as staff.

Concept papers are used with constituencies to develop the most efficient approach to resolving feasibility issues of the study (or redirect efforts). The data collection in the "research process" stage may involve constituencies in monitoring the efficacy of the research process, but additional steps can also be introduced to moderate potential effects of bias. Once research data are acquired and verified, analysis, reporting, dissemination, and applications most often are the stages in the cycle when constituencies and researchers come to consensus about what the research results do and/or can mean. Collectively, the constituents-researchers move toward drawing fully and accurately upon the empirical findings and their combined experiences to identify potential products and alternatives that do not violate the integrity of the research findings.

Synergism. As the figure suggests, the research methodology is iterative and regenerative. A promising finding may stimulate a valid application for an individual or for rehabilitation practices. Reviews and reanalyses suggested by the Committees may lead staff to eliminate competing hypotheses. Likewise, the combination of valid research and such "more inclusive analysis" may cause the research and developmental activity to take a different bent from that initially considered. Constituent input and their perspectives, therefore, affect how issues are formed for research, intervene to acquire quality data, keep the analysis focused on the salient issues, promote more sensitive understandings of meaning from research, and may well stimulate both researcher and constituent to be creative on planes neither of them might have attained separately.

Required Scientific Rigor. The use of this participatory methodology is to provide external reality checks so that there is a higher potential for solving important problems in rehabilitation. No matter how sensitive staff are and how sensitive they become to real concerns, if the research technology is compromised, the results of that effort are nil. Not only is the validity of the specific research findings seriously threatened but the utility and value of the effort to solve problems is more than just suspect. Failure of researchers to continue their responsibility for retaining the rigors in the research will be paid for by constituencies who put hopes upon research. Invalid research yields invalid answers and is a waste of money, time, and hope.

Interrelatedness of Research Studies. The Center's program is a 5-year network of closely related approaches for achieving solutions to rehabilitation problems that may be used in many different kinds of communities and by

practitioners and consumers from differing walks of life, cultures, and disabilities. The program offers a variety of studies that cross over (a) the need to derive practices that will substantially improve the delivery of rehabilitation services (particularly when it comes to vocational and community integration goals), (b) the need to enhance the capacities of individuals with disabilities to engage in and command greatest control over their own rehabilitation destinies, and (c) the need to provide local community-based rehabilitation with programs that assure the presence of resources that are of greatest value to citizens with disabilities.

The program focuses on putting "what works in community-based rehabilitation into practice in local communities." It starts with what is known and adds to that the creative thinking of practitioners and consumers and what they are able to show as workable. It provides a wrapping of rigorous demonstration studies to extract, document, and promote "what works."

As discussed later, technical assistance and training are made available to practitioners and consumers to make use of these demonstrated practices. Technologies and materials that can be used to improve rehabilitation delivery are developed. Advocacy among constituencies of community-level rehabilitation is directed at helping them create a broader vision of what can and/or needs to be done to achieve the improved community-based programming. Advocacy with consumers and providers is intended to help them implement practices that result in integration of people with disabilities into the productive work force and as contributing members of the broader social milieu. These are all parts of the Center's efforts to achieve adoption of research applications.

Studies are designed as a progressive series and deal with successive pieces of one or more priorities. In combination, they can have impact both on how well individuals with disabilities achieve goals for themselves and how community-based providers help them achieve these goals. The studies (a) examine the value of alternate means of providing employment with quality wages; (b) examine methods to increase the participation of individuals with disabilities in decision making and management of community-based rehabilitation; (c) compare practices that may expand the technologies providers and consumers can use in choosing among alternate program models; and (d) examine techniques that may increase access to community resources, including financial, employment, independent living, and case management (facilitation, access, coordination).

Priority Driven Studies. The studies deal with interrelated issues identified

under one or more priorities as identified by the National Institute for a funding cycle. Each is designed to help answer problems and research objectives across the Center's total program. For instance, outcomes regarding alternate employment practices can also provide answers about how consumers take on greater direction in their own rehabilitation. Likewise, as barriers to the participation of individuals with disabilities in rehabilitation management are identified and solved, these results can also suggest how consumer needs for case management might be met in community-based programs.

Knowledge Transfer and Applications

The priorities set out by the National Institute relate both to research and to training and dissemination activities. The **Knowledge Transfer and Research Applications Component** was designed (for organizational purposes) to complement the **Research and Development Component.** Keeping in mind that this component is imbedded in the participatory methodology, it makes use of the techniques of training, dissemination, and technical assistance to translate and move practical information from research into useable forms and into the hands and practices of consumers and rehabilitation professionals.

This component was conceived to keep us mindful of and to get us to deal in concrete terms with getting maximum impact. Materials, technologies, and information that assist consumers and practitioners to understand the changing phenomena of community-based rehabilitation need to be made available throughout the 5-year cycle. As a staff and Center, we create awareness of the proposed work; seek additional input to help guide potential media and applications; and identify needs for specific training, conferences, distance learning, and seminars for consumers, practitioners, and other concerned individuals. Consumers and professionals need access to useable, relevant information - the kind of knowledge and the consequent skill that can foster empowerment, whether the individual has or does not have a disability.

Historically, Research and Training Centers have relied primarily on "flow-through" methodologies to transfer new knowledge to practitioners and, subsequently, to the benefit of consumers of rehabilitation services. These methodologies presumed that new knowledge is inherently valued and will be accurately assimilated and applied by potential users with very modest interpretations by the potential practitioner-user or with modest assistance of a consulting trainer-technical assistant. Having to depend on paper documents that are concise enough to encourage the adoption of innovations leaves too much to the interpretation of individuals not privy to the depth of knowledge available to

the original researcher-developer. What may appear to be a reasonable use of data may not be as clear an application when the researcher adds the explicit limitations noted through research. Or, as is probably more often the case, when the application is conceived quite independently of the researcher and relies upon applied knowledge of what is thought to be realistic extensions of the research, inaccuracies can occur.

Involvement and Knowledge Transfer. The more new knowledge is in contrast to commonly accepted practices the less likely it will be adopted through passive methodologies in the research-to-application process. Rehabilitation professionals and educators must be more actively informed and involved in the research process to encourage field-based transfer.

Our alternative to the traditional "flow-through" approach is presented in Figure 2. Our approach involves constituencies with us and makes use of their "expertise" to transfer and apply ideas, innovations, and generalized concepts derived from the studies. If they are to make accurate interpretations and applications of research generated information and reliably transfer that information for people with disabilities participating in rehabilitation programs, the potential user of the innovation must know the parameters for that innovation.

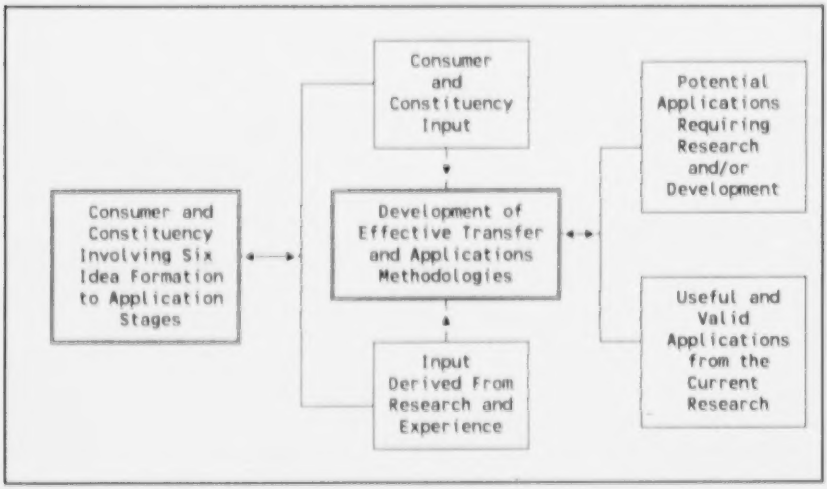
Consumer and Constituency Involving Six Idea Formation to Application Stages
Consumer and Constituency Input
Development of Effective Transfer and Applications Methodologies
Input Derived From Research and Experience
Potential Applications Requiring Research and/or Development
Useful and Valid Applications from the Current Research

Figure 2. Model for Knowledge Transfer and Research Applications

There must be involvement of consumers and other constituencies in the training, technical assistance, information packaging, and dissemination activities than is typically the case with "training units" of Research and Training Centers. As is the case for increased involvement of constituents of the research throughout the research process, so too must the Center's methodology require maximum involvement of consumers and other constituents when designing and implementing training and dissemination. Use of the training and dissemination skills of a Center's staff can materially improve how effectively the input from constituents is achieved and how well they are involved. Inclusion of, access to, and use of those same skills provide added assurance that both the knowledge transfer and the need to devise applications get attention from the very beginning of research development.

Multiple Approaches to Transfer. This methodology recognizes that substantial change in practice does not occur by using a single methodology. Rather, significant change occurs over time and requires the variety of methodologies appropriate to the readiness and capacities of organizations and individuals to adapt to and to acquire new resources, skills, and behaviors needed by them because of innovations. For example, short-term training can aid implementation of innovation if both the trainee and the organization are ready to make use of the new skills acquired through training. On-site, technical assistance can help promote needed change if it has been carefully planned beforehand, if staff are prepared for it, and if specific actions are identified and followed through by the organization and staff. Publication about an innovation will inspire advocacy for implementation if the audience of the publication can access information and are helped to see, through example, how the new way of doing things can work for them and may actually help them more consistently and efficiently achieve their goals. The level and quality of constituent involvement in this component is no less than in research activities.

Clearly Defined Audiences and Benefits. The audiences of the program are both community-based staff and consumers. The program is expected to sensitively accommodate and materially aid the increased expertise and quality of rehabilitation practices of individuals who have diverse, complex disabilities and who desire to achieve community-based employment and integration goals. The training and technical assistance are provided to community-based staff from all geographic areas of the country (e.g., rural, small communities, urban).

Accessibility of Products to Increase Applications. All published materials from the Center are made available in alternate formats appropriate to the needs of persons with disabilities and their families. These formats include large print,

closed caption video, audio, digital formats, and braille formats. All materials used in training and technical assistance (including programs and documents used in conferences sponsored by the Center) are prepared in formats appropriate to the needs of participants. All training, seminars, conferences, and meetings are provided in fully accessible sites. Library and services available through the Center to students and constituents of the Center are also highly accessible (e.g., via computer, alternate formats, closed captioning).

Highest regard is placed on ensuring access to training opportunities without economic constraints. Sites are selected for convenience and reasonable costs for the majority of expected participants, even when the program is self-supporting. Where cost for registration and/or access to the opportunity represents a burden to the individual, alternate resources are sought. Where feasible, separate funding to ensure such access is pursued (e.g., alternate funds to support, building waiver-travel costs into conference budgets, support travel for consumers).

Every report or monograph is made available to professionals, consumers, and policy makers, and journal articles are available from the respective journal publishers. All reports and monographs developed by the Center are available in alternate formats (e.g., large print, braille, audio, digital, subtitled video) as needed. Copies of products from the Center are deposited in every relevant library and clearinghouse; to every related continuing and preservice professional education program; to regional and federal agencies; to members of the Center's advisory, review, and input panels; to other Research and Training Centers with related research priorities; and to selected individuals and organizations that make direct use of the findings.

All sites used for Center-sponsored conferences, symposia, and study groups are accessible, both structurally and with regard to costs for participation. Curricula, agendas, papers, or materials developed for presentations at conferences are also available in alternate formats so as to be accessible to all individuals with disabilities. When needs are known in advance of a meeting, they are met at the site. Also, upon request, materials used for presentations are made available in alternate formats following presentations. Additional accommodations are made so that individuals with disabilities who wish to attend such meetings are able to fully participate.

IV. The Case for Involving Constituents[4]

The case for involving constituents is not based in any way upon social or political correctness. The reasons to do so do not include "doing the right thing" or "meeting some quota" or tokenism of any persuasion. The case can be made upon respect for and mutual valuing of contributions that differently skilled individuals can provide. The case is made on the basis of need to get more real solutions to real problems of disability.

Constituents have something to offer that may, when carefully brought into play, make it more likely that the time and dollars we put into research do more to foster a "better reality." This is, in sum, the case for inclusion. How such involving research is done, whether it is economically feasible, and how we go about controlling for invalidity that may be introduced are all issues of method, procedure, and policy. Those issues must be addressed separately from arguments of "why to involve constituents."

Constituents as Players in Different Roles

One way of looking at constituents is that they are "players," each of whom brings something unique to the search for workable solutions to the problems of disability. The players (be they consumer, practitioner, or researcher) are all interested and demanding of improvements and solutions. Research can offer important parts of the solutions. As each of them becomes an "insider," he/she learns to make better use of research. They may develop sophistication in synthesizing present understanding and limited solutions to rehabilitation needs, in clarifying and prioritizing needs, and in designing options with new knowledge from the research. Collectively, they share a common hope to achieve these solutions. In consort, they can be integral to designing, executing, and translating research that has high relevance and appropriate scientific merits. Oftentimes, they are the people who promote "things that work," including research findings that may not appeal to "popular" perceptions of what is possible.

Consumer and Advocates. Consumer refers to those people who will be most directly affected by the research (e.g., as subjects) and by a practice that might derive from the research. Consumers include the person directly affected

[4] This section is adapted in part from "Strengthening Applications From Research Through Involvement of Consumers and Practitioners" (Menz, 1992) and sections contributed by the author to the Institute on Rehabilitation Issues "Consumer Involvement in Rehabilitation Research and Practice" (1992).

by disability, like a client and/or people indirectly affected, like significant family members, friends, or employers of people with disabilities. In general terms, they are the "individuals with disabilities" or others significantly involved in improving the quality of life of such individuals outside the "systems of care." Consumers bring sensitivity, history, experience, and compassion toward the possibilities and consequences of a disability. When we speak to consumer involvement, we will be speaking of their involvement consistent with their ability to share, participate, and lead the research-development effort. Advocates often share in the intensity and sensitivity to need but also possess broader expectations of value and potential application from a variety of disability related efforts, including research.

Practitioner and Providers. Practitioner and providers is a broad category of professionals and paraprofessionals involved in affecting, causing, controlling, or delivering the "systems" of care and rehabilitation. They are inherently involved in one way or another in the applications from "research" and innovation. We include here the professional rehabilitation counselor, the peer counselor, the rehabilitation administrator, the public policy advocate, the social or welfare service bureaucrat, the case manager, the job coach, the trainer, the proponent, and the opponent of seemingly needed change, the teacher of consumers, the teacher of other practitioners. In real terms, these are the people who make innovation go or who stand in front of "system-society-institution-wide" adoption of innovation. They possess knowledge, skills, and experience about what "has been" reality and about what has been effective and/or ineffective practices for people with disabilities. When we speak of practitioner involvement, we are not speaking narrowly about one "group" of people in a service delivery unit or program. Rather, we are speaking of the person(s) who can advocate or implement or access resources to put innovation into place that may reduce the impact of disability.

Research Applications and Advocacy. Researchers have training and experience in the philosophy, theory, and technology of research processes. They are inherently involved in finding or creating "realities" that can be replicated. They are skilled, informed, and competent. Above all, they are concerned about acquiring new knowledge, eliminating myths, and achieving functionally valid improvements in this process called rehabilitation. Distinctions between quantitative and qualitative researchers, between experimental and evaluative researchers, or between researchers according to their preferences for a method are inherently inappropriate.

While they oftentimes have many of the answers to questions that both

practitioners and consumers want, they are apt to be cautious, tentative, and conditional when sharing and applying those answers. Steeped in the traditions of scientific inquiry and possessing a high regard for the processes of systematic inquiry, they are of considerable value when they impose order and quality control in the search for innovations and solutions. Also, as we speak of researcher involvement, we do not make any assumptions about their position in a hierarchy, but rather recognize their unique role and shared responsibilities in the search for real solutions to real rehabilitation problems. As with any constituent in this process, their functional roles may vary widely, depending on what expertise is needed to address the underlying disability issue.

Differences in Motive and Perspective as Common Ground

> ***Constituencies*** *are people and organizations that have a perspective about what needs to be accomplished in rehabilitation, through sound rehabilitation research.* ***Beneficiaries*** *refers to individuals, organizations, and/or processes that will make use of research findings.*

Figure 3 attempts to portray how three types of players may differ in their motives as they seek help from rehabilitation research or may begin to take part in it. The figure is intended to suggest how they have different hierarchies of needs, different priorities in rehabilitation, and consequently, different priorities for rehabilitation research. The figure suggests the intensity that consumers have for solutions of individually valuable impacts of research on disability, and for increased access to options or solutions that are understandable in the language of real people.

In many regards, the practitioner and consumer hold similarly intense feelings about research deriving solutions, but their priorities may differ in subtle ways as practitioner motivations may be for knowledge about how those same solutions can be applied on behalf of consumers with many different kinds of rehabilitation problems. The researcher profile, in contrast, may likely have motives that reflect what they do well and why they continue to be involved in rehabilitation research: underlying concern for disability issues, but overriding priorities to do research that is valid, builds new knowledge about a disability issue area, and is scientifically valued. Though there are such relative differences among these profiled variables, there are grounds upon which they can truly complement each other.

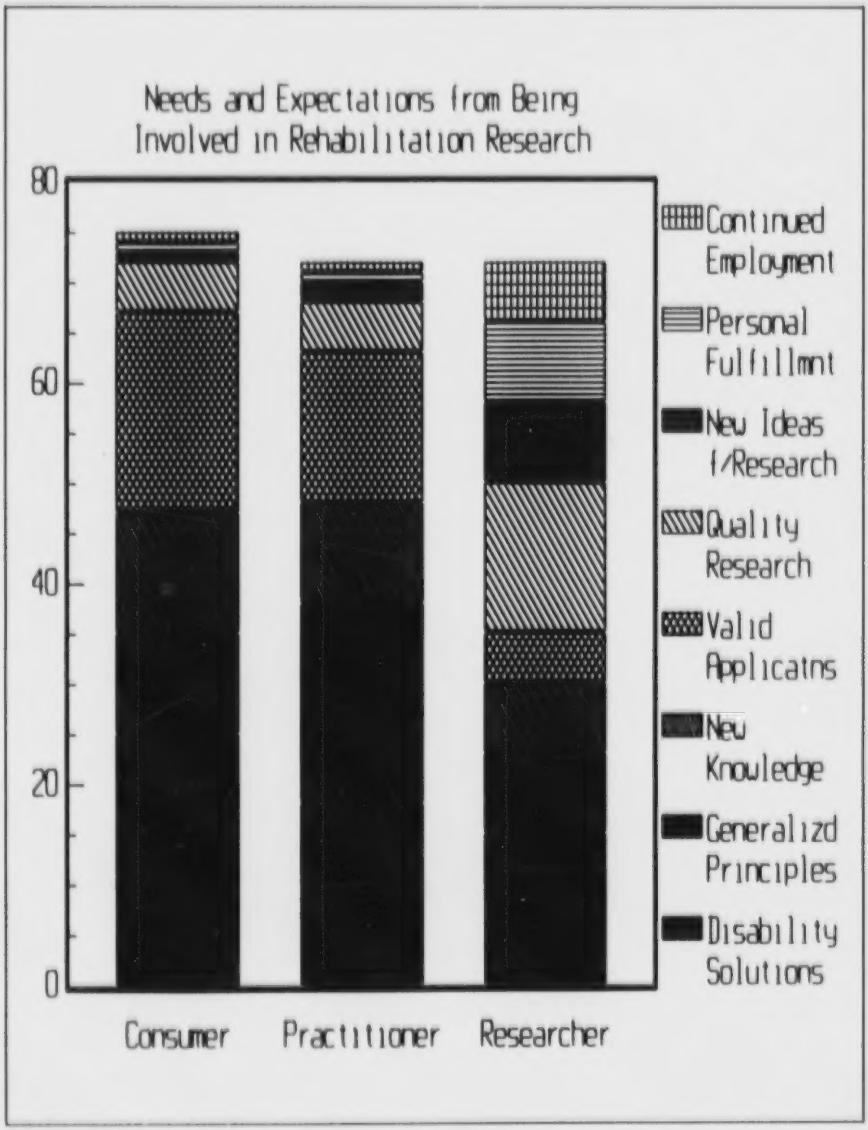

Figure 3. Relative Differences in Motives and Needs Among Constituencies

The common element that runs through their relative differences in priorities is a common desire for a better reality in which disability need is accounted for, but is not the defining variable. Such a common goal involves them in searches for reality of need from disability, comprehension of disability and its interaction with the environment, reality of possibilities for individuals and communities, reality of resources and changes to permit realization of individual capacities, reality of public awareness and concern to change how they relate to disability, and reality in the search for solutions.

Constituents add to the process unique values because of the differences they have in their perspectives about problems, priorities, processes, utility; about how the work of research gets done; about their roles in rehabilitation research; and about what a quality of response to problems of disability might look like. Yet, while those perspectives and motives differ, each of them expects that research, when correctly and sensitively conducted, can yield significant solutions, answers, or a variety of valid options. The differences they bring in motive and in perspective to the research endeavor are what might improve the quality and applicability of rehabilitation research.

Disability Issues Determine Constituencies

A sample of the variety of constituents that are concerned with our program of research is listed on Table 1. The table largely portrays the groups and individuals with whom this Center works and whom our mission dictates our research or training must impact. The groupings are under broad classes based upon how they would hope to make use of research or, if you will, the driving need they might have for using and being involved in research: Those who have need arising directly from disability, those who work with them to solve needs, those who advocate throughout the systems and political arenas, and those who use and apply research in intermediate ways. Of course, many of the individuals who become involved as constituents in Center activities oftentimes have more than one constituent perspective.

This arrangement is but one way to look at constituents and helps us when we are trying to initially identify individuals to work with us or to add or supplement advisory sources to the Center and specific projects. The disability issues or research issues stemming from those set parameters help determine who the constituents are and which individuals should be sought to represent each constituent viewpoint. There are no magic guidelines to identify them. There are no meaningful formulas for how many of any given "type" is necessary if the research is to be constituency involving. Each of us begins to define

constituencies based around the program of research and the audiences we anticipate benefiting from it. As the research evolves, constituencies become clearer, and may actually change. Too, individuals representing constituencies may change during different stages of the research-to-applications cycle.

Table 1. A Classification of Research Constituencies

Center's Research Constituencies	Examples of Sources From Which to Draw Participants
Consumers of Rehabilitation. Those directly affected by disability needs of individuals and to whose interests specific research would be applied. Sometimes suggested as the ultimate or end-user of research.	Individuals with specific disability needs. Individuals with similar disability needs. Family members who have disability related needs. Individuals without disabilities who advantage from rehabilitation program technology. Agencies that are customers of rehabilitation. Communities addressing needs as a result of disabilities. Employers with jobs for individuals who may have needs. Community service organizations. Public service enterprises.
Practitioners and Providers. Those who apply research results on behalf of, in interest of, or with individuals with disability needs. Professionals and paraprofessionals and organizations that make use of research in applied practice or in management of rehabilitation-related services.	Individual rehabilitation professionals and paraprofessionals. Professional disciplines. Allied rehabilitation personnel. Community-based service providers. Agency and facility-based programs. Protected employment programs.

Table 1. A Classification of Research Constituencies

Center's Research Constituencies	Examples of Sources From Which to Draw Participants
Advocates for Disability Issues. Those who represent or work on behalf of the interests of people with disability-related needs. Individuals, public and private organizations, and other entities promoting and supporting needs of individuals and groups of individuals with related disability needs. Interest in research for applications to real problems, fiscal issues, and public policy formulation.	Individual advocates for persons with disabilities. Advocacy organizations. National Council on Disability. Consortium for Citizens With Disabilities. National Rehabilitation Facilities Coalition. Accrediting and certifying bodies. Special interest lobbyists. Cultural and special interest groups. Individual public policy leaders and influencers. Legislative aides. Congressional and other elected officials. Public rehabilitation agencies and staff. Bureaucrats and other public agencies. Insurers, funders, and fiscal sources. Selected federal, state, community public agencies.
Research Applications and Advocacy. Those who build upon information, knowledge, and results of research. Intermediaries in the application of research to expand knowledge, to solve specialized problems, to devise devices and practices, and to get knowledge available and applied to disability needs.	Individual researchers. Research confederations. Professional associations. Professional disciplines affiliated with rehabilitation. Professional, certifying, and licensing organizations. Product and service developers. Commercial products designers. Commercial distributors. Preservice rehabilitation educators. Continuing education, trainers, and educators. Clearinghouses, libraries, and public archives. Regional information exchange programs.

V. Constituent Involvement at Different Stages of the Research

Perhaps, because I have spent so much of my professional adult life in and around research, I like to think of research as adult learning at its best. To me, it is a way of looking at the world around me and verifying what "seems to be" (hypothesis testing) and discovering what might or can be (invention and innovation). It is a process — a way of analytically and experientially learning from the real world. As this adult learner, I use substitute tools (designs, instrumentation) to get at truth, knowledge, and viable possibilities.

The rules in the process are ones that have been developed through considerable testing over several centuries and across subject matter as diverse as philosophy, physics, anthropology, and rehabilitation. Whether we are looking for new knowledge, verifying what we think "is," or trying to come up with better principles of community-based rehabilitation program administration, we have a fundamental requirement as a researcher (a.k.a., adult learner). That requirement is that we must above all else be concerned with the integrity of the research result, that is, its validity and replicability.

In order to do this our research processes, or rules, help us to "objectify our observations of evidence." In research we do not objectify people or events. They are real and are the central concern in most of rehabilitation research. Instead, we put the burden on the collected evidence that best separates what is or is not true about those events or people. Unfortunately, I must agree, we tend to confuse objectifying with distancing ourselves in practice and through our language.

The point of view I offer here is not intended to get into the continuing debate over objective and subjective measurements. I suggest that those arguments, as far as research in rehabilitation goes, are not pertinent to the case for or against constituent involving research. I suggest that the rationale that the traditional research paradigms "depersonalize" or make people "objects" and so, therefore, a new paradigm should be used (i.e., action-oriented research or some other "less rule bound" approach) merely pits methodologies against each other. That argument misses the important point in this revolution in social science research: People with vested interests know a lot more than they have been credited for, they can be discriminating participants, and their participation may do more to move invention (creativity) to innovation (usability). The search for solutions to issues in rehabilitation should take advantage of the full complement

of research methodologies and expanding technologies.

There is a real potential that better solutions to important issues will be brought into practice when constituencies are more intimately involved in the research process. How to effectively do so needs to be operationalized. The need for more applicable solutions is too great to entertain polemics built upon a point of view as to what is research and how it should be done — whether those polemics are for a methodology, who should be the researcher, or some formula approach to how constituents must be involved. Such polemics are too apt to generate populist (not pragmatic) methodologies, socially acceptable (not substantiated) answers, and diminished (not expanded) numbers of replicable solutions.

In designing our constituent involving model, we based it upon the traditional research process. Very different research designs (e.g., quantitative, qualitative, experimental, survey, anthropological, ethnographic, synthesis) are applied within this process depending on the issue and how that issue is clarified as a research problem by constituents. The traditional research process is considered as five interrelated, functional stages: problem formulation, research planning, conducting the research, analysis, synthesis and dissemination. To ensure that the "cycle" is completed, a sixth stage was added in the Center's constituent involving model: transfer of research-based applications. This added stage helps us know when the "research is responsibly completed," a benchmark measure that is at least as meaningful as a publication of the final report. More importantly, it brings clearly to our attention (constituencies included) validating evidence of our enterprise: We all know whether, where, and how we have achieved our goal of "research that can be applicable or translated into practice."

When each of these stages is discussed in terms of the functions that take place within the stage, there is the tendency to view the stages as discrete, when in reality they are quite interconnected and symbiotic. Also, by viewing them as discrete, the "action" or "translation to applications" that can occur cumulatively and during any stage is often lost sight of. In the methodology proposed in this publication, "action" is intentionally imbedded within each of the stages and reinforced both by an established assumption that application or actions must occur and through specific efforts to have constituents and researchers share in the process and share in the responsibility to achieve meaningful changes in rehabilitation practice.

Each stage is discussed separately below. However, keep in mind that the six stages are interrelated as depicted in the model described in Figures 1 and 2

in a Chapter III. It is important that constituents involved in the research process understand these stages. That understanding is important not so much that they must be able to master all of the functions but so that they can help guide how the different roles each of us plays are seen and made the best use of a given research endeavor. In Chapter VI we examine the many different functions individual constituents can meaningfully perform. Here, my purpose is to suggest how different constituents are meaningfully involved, how control changes hands (so to speak) during the process, and how ownership of the research and commitment to apply it can come about.

Formulation of the Problem

This stage oftentimes begins well before anyone who will be involved realizes that research will be undertaken. Most obvious is the point when the "research priorities" are established for a funding agency (e.g., the National Institute). This stage involves both a narrowing and broadening of the understanding of a "problem or experience." It is somewhat like taking a personal problem (e.g., "my brother has AIDS") or a general social concern (e.g., "too many people with disabilities are on welfare") or a specific concern (e.g., "access to and benefits from vocational rehabilitation for Blacks and Hispanics are substantially poorer than for Anglos") and considering it, as fully as possible. Collectively, the constituents (e.g., persons with a disability who are also from minority backgrounds, rehabilitation counselors) know more about what is involved in the problem because of their different perspectives and different sources of information (e.g., experience, training). Reasonable priorities among the many issues that any given problem might raise can be set. A working consensus about what the "important problem is" can be achieved as the many perspectives are interrelated.

This is the stage in which the non-trivial issues are separated from the truly trivial and one starts to see how potential solutions to such problems would be of more or less value. It is at this stage that one should be considering whether the identified problem is actually a problem that is worth pursuing, whether knowledge is sufficient to "invent" a solution, and whether there are the kinds of resources needed to do justice to the issue. It is also at this stage that each constituent should begin to anticipate how the solution to an important problem might lead to some change in the way things are done, some new intervention, or some new preventive step ... or anticipate new research questions that need to be pursued in a programmatic fashion. In effect, as the problem is clarified, each player begins to anticipate and begins to plan applications of the research, nascent though those plans would be at this point.

Table 2. Constituent Development of a Researchable Problem

The initial statement of a personal problem. My brother and many of his friends have AIDS. He is scared and his family and friends want help.

The research problem development. The informed perspectives of consumer and practitioner and researcher are explored, integrated, cleaned up, and united to form a rational picture of what it is that needs solving and what such a solution might look like.

> The consumer sensitizes the others to the real experiences of learning of the diagnosis, personalizing and rationalizing it, denying and projecting anger and fear, dealing with acquaintances, discovering the economic as well as health consequences.
>
> The practitioner sensitizes each to the economic and rehabilitation limitations within current systems and the seeming pattern of change among known cases.
>
> The researcher may share research information, facilitate a mapping of the different perspectives, and relate those to where he/she senses other medical and social research will be going on during the period of time they all may be concerned with this issue as a research problem.
>
> The three arrive at a consensus about the important issues, priority among those issues, and a general sense of the scope of a problem that can be reasonably addressed through research.

The resulting statement of the research problem. What are the social, economic, and rehabilitation consequences of AIDS for males 21-40 in Peotone, Illinois? To what extent do age at onset, education, sexual preference, availability of supports, medical access, and prevailing community values increase the adverse consequences of the diagnosis? To what extent are attitudes and responsiveness of persons within the individual's circle of acquaintances (family, friends, co-workers, churches, employer) instrumental in the individual dealing with the disease?

Identification of tentative research applications. Public information on the etiology of AIDS, risk in contagion, limitations to function. Intervention strategies for co-workers and families, for controlling the day-to-day changes in capacity. Rehabilitation strategies for job restructuring, personal estate planning, grief counseling. Organizations and resources needed to be prepared or alerted to the potential solutions that this might bring about include churches, social agencies, area clinics. Additional "insiders" who should become involved in the research stages now includes counselors with active AIDS caseloads and emergency care workers at area clinics.

Each of the players (or constituents) has something different to offer at this stage. Each has a unique perspective and scope of contributions. The consumer has depth of knowledge about the course of his/her response and the consequences coming from the disability. The practitioner has experience in use of current practice and knowledge of the limits of our present technology in attempting to trace or ameliorate those consequences. The researcher may have a broader knowledge of the accumulated research on relevant issues that surround the problem of interest. And, while the researcher will have the analytic skills to help the group separate the parameters of the problem, it will be the depth of personal and practical understanding of the problem that the consumer and practitioner introduces that will decide whether that technical expertise is more or less worthwhile.

This stage helps each participant better understand the context of a problem, the interdependence of personal and professionally based factors, and some of the possible factors or variables that might be controlled in a study. There is a collective and rational understanding of the problem. The outcomes of this stage are (a) identification of a priority topic for study; (b) identification of constraints, opportunities, causal factors, environmental constraints, relevant practices-issues to consider; (c) identification of potential utility and utilization plan; and (d) creation of conditions that will help assure greatest yield from the research.

By having "gone through this stage" does not mean the player's understanding of the research problem will not change. Research, as is suggested here, does not progress as a series of discrete and predetermined steps as defined under some unchangeable linear model. While research progresses from problem identification to the development of a research design, to its execution, and to an interpretation of the research findings, problem identification is almost serpentine, insinuating itself throughout the other research stages. Understanding of the "problem" continues to be shaped throughout as new knowledge is introduced from the research results and as the informed partners invest more of their growing knowledge of it into the research process. Sometimes, one of the most important outcomes of the research process is achieving a clear, consensual understanding of the research problem among the players who initially came to the research with their indigenous perspectives.

Planning the Research

The term "plan" has an especially important meaning in rehabilitation research, where application of the research in practice is intended. A research plan is a formally written collection of guidelines and principles that control how

the study of the problem is carried out. It outlines an agreement among the participants about resources that must be acquired and how those resources will be responsibly used. This plan places restrictions on how broadly the inquiry will go, how necessary research data will be acquired, and how data are dealt with once they have been obtained. It establishes quality controls for these "inquiries." It is not a device to constrain the quest for valid answers to the real research problem. Rather, it is a device intended to contain enthusiasm and reduce the influence that comes from personal-perceptual biases about what is and isn't real and what is replicable. The attributes of such a plan include the following:

1. Defining interventions or treatments that will be part of the research;

2. Formulating research questions to guide the research or hypotheses that will be tested during the course of the research;

3. Identifying relevant independent and dependent variables that must be considered in the research;

4. Identifying relevant sources for needed data (i.e., the populations) and appropriate sampling techniques;

5. Selecting or designing any needed instrumentation or technology;

6. Designing quality control checks;

7. Piloting and verifying the utility, appropriateness, and inter-dependence of the above; and

8. Preparing a procedure that operationalizes and efficiently manages the course of the research, yields valid findings with minimal errors due to poor planning or bias, and suggests potential applications.

Characteristics of a good research plan in rehabilitation (and probably in any other scientific area) is that of "sensitivity and flexibility." By this one means that the research plan, while keeping attention to the primary problem, has built a capacity to grasp such data that will better align the research activities to the more pertinent aspect of the problem. By including "sensitive checks" throughout a research plan, the research can remain focused on the "research problem" and not become bound by *a priori* assumptions or confused by the seeming importance of a single element within that plan. A good plan provides

(a) signals that clearly indicate that the research is going smoothly and need not be interrupted; it also (b) signals when the research is not fruitful and limits any further expenditure of scarce resources, and (c) signals when the research is off-target and identifies what might need to be done to refocus the effort. When such monitoring is followed closely, the plan can be rationally adjusted.

There is considerable literature that a competent researcher can draw upon when preparing such a plan. However, the researcher need not always take the lead for translating the research problem to a research plan. Much planning can be improved when alternate perspectives are incorporated and the evolution of planning activities are shared among constituencies. From each participant's perspective there are several abiding questions that should guide participation at this stage, whether when addressing a given element or the overall plan. From their perspective of the problem as consumer, as practitioner, or as researcher, each participant has much to offer: (a) input to the plan, (b) evaluation of the plan, and (c) commitment to participate in the plan as suggested below.

Table 3. Constituent Participation in Planning

Input to the Plan	
What would I propose for any of those elements of the design?	Is there a more efficient or effective way to go about this research?
Are there issues that I am aware of that should be considered or addressed in this plan?	Is this plan sensitive and respectful of the needs, rights, feelings, and capacities of the people involved?
Do I understand what is going to take place and why it is being done in the planned way?	How well do plans for application coincide with the research plan?
What is my understanding and opinion about each element?	How might these plans be improved?
Does this plan make sense?	**Commitment to Participate in the Plan**
Evaluation of the Plan	What sources or resources might I identify to effectively achieve the plan?
Is what is in the research plan relevant to the problem?	Which of the participants has the better resources (e.g., access to subjects) or capacities (e.g., knows how to talk with certain groups) to do what is required?
Can this plan work?	What part(s) should I or others play in carrying out the research?
Does this plan include enough checks for monitoring to ensure success?	What should I watch out for as I monitor the project's progress?

Conducting the Research

This stage is the period of time when the data needed for decision making are actually acquired. The agreed upon plan is operational, the plan is modified according to monitoring results, and, quite likely, understanding of the research problem again grows or is refined. This stage is probably one of the two (analysis being the other) most characterized by "objectivity" and "compliance to agreed upon rules." Quality control is its hallmark and can assure that appropriate data are sought and accurately observed and reported. Monitoring, as described above, fully envelops the specific activities in this stage. This stage begins with selection of samples, implementation of interventions or treatments, and collection of needed data or evidence. It ends when data have been verified and codified for analysis.

Traditionally, this stage has been left to the researcher, with minimal participation by constituents. Participation by them in this stage is not only possible but quite advisable when the concern is to arrive at relevant applications from research. There are many specific ways in which both consumers and practitioners might be meaningfully involved. At least two major forms of involvement though are desirable.

One form of involvement is in monitoring implementation of the research plan. Consumers and practitioners can monitor how the plan for research unfolds and apply their perspectives to how any deviances from the plan are accommodated. To a great extent, consumer and practitioner participation may be especially beneficial as they are less likely to be enamored with details of the research process. They may be more "objective" and cognizant of "compliance with the rules" and more apt to promote appropriate changes to the plan.

A second form of participation is in carrying out selected parts of the research plan. While certain activities will of course require trained researchers (e.g., in observing and recording of behaviors, in interviewing, in administering a treatment, in coding data), many of the activities can be carried out by "para-researchers." In studies focused on people with severe disabilities, those other than the researcher may have the depth of sensitivity that one gets only by having a disability or by having worked with numerous people with disabilities.

In these circumstances, the researcher may not be the best "observer and recorder" of data. They may be too limited in experience to document and describe the "therapeutic interventions" that took place. Ability to access people and their thinking may be limited. Awareness of nuance, regardless of the

instrumentation, may not be sufficiently on target. In these cases, the better observer-intervener may be the consumer or the practitioner trained to conduct the needed interviews or code samples of behavior. The researcher will do better to set procedures and provide the training to maximize validity in data collection and interpretation.

The researcher has an important advantage when it comes time to analyze and interpret research in that they have the opportunity to develop an appreciation of the apparent quality and limitations of the data that have been obtained in the research. Likewise, the consumer-practitioner as researcher has the advantage of being able to relate the meaningfulness of observations they acquire back to their prior experience or knowledge. These kinds of understandings are ones that are difficult to relate and almost impossible to transfer to others.

Yet, both types of experiences afford the "researcher" subtleties with which to work in the evaluation of the research findings. These experiences provide understanding and afford reasons for caution as they subsequently work with quantitative and qualitative summaries of findings. As informed and trained participants in the research activities, their involvement can enhance and sensitize them to the possibilities and generalizability of the research for practice, as well as make them aware that the research has perhaps not answered all of their most personal concerns.

Analysis and Reporting

The purpose of this stage is to reduce the mass of discrete and/or interrelated bits of information (i.e., research data or evidence) to a communicable whole in keeping with the research problem and research plan. The objective is to achieve clear, concise knowledge about the problem. Analysis and reporting return to the purposes, hypotheses, and major questions of the research with evidence that assists the participants to separate what is true (i.e., probably true) from what remains unknown or uncertain given the research method.

Paralleling the literature on research design, there is an equally impressive technology available to help researchers achieve the analysis and reporting process in a systematic and quality controlled manner. As in data collection, this technological base guards against simplistic, inappropriate, and unwarranted conclusions, given the quality of data available to this decision-making phase of the research.

Too often, though, varieties of statistical and graphic tools are inappropriately

applied or not in keeping with the research design. Worse, this technology often takes on a life of its own and becomes a source of "impression" and "illusion," lending little to the communicability of the research: Uninterpretable tables of means or percents; statistical tests that are inappropriate to the research design; interesting and attractive graphics that do not relate to the issue or suggest meaning that is not supportable by the research; use and reporting of high-powered statistical analyses applied when a simple presentation would suffice. Complexity in presentation is confused with sophistication and elegance or simple presentations are assumed to be accurate renderings of the research findings.

Participation of constituents in this stage can again moderate any tendencies to be more overly involved with "data manipulation" and less mindful of the applications of those data. As in planning research, constituent perspectives can provide guidance that should improve fidelity and usefulness in how data are analyzed and presented. These should guide participants as they become actively a part of this stage of the research: (a) analysis of research data, (b) presentation of the findings from the research, and (c) interpretation and conclusions drawn from the presentation as suggested in Table 4.

The outcome of this stage may be (a) appraisal of changes and implementation needs; (b) identification of likely alternate methods, data, and strategies to achieve change; and (c) identification of some ways to disseminate findings. All players should know what data were found and clearly understand what they might mean to them for changing or enhancing practice. The outcome of this stage must be consensus among the players as to what the research has yielded as solutions.

Synthesis and Dissemination

Synthesis goes beyond appropriate publishing and accurate interpreting of the data in relation to the identified research problem. Synthesis prepares important messages for the audiences most interested in those messages. Dissemination delivers messages to the right audiences using mechanism(s) appropriate to both message and audience. There are strong parallels between this stage and the "problem formulation" stage. In some regards, what takes place during synthesis and dissemination is an evaluation by constituents of what has become known about the "problem" and exploration of what they might do about that new knowledge. In this stage a shift occurs from seeking answers to putting together strategies to get research used or, if one might, to "invent" ways to achieve the end initially desired when the research was started.

Table 4. Constituent Involvement in Analysis and Reporting

Analysis of Research Data

What is the most direct way to analyze these kinds of data?

What safety checks are or should be in these analyses (i.e., to prevent incautious conclusions)?

Do I understand how and why the data are being analyzed?

Does any of this make sense to me?

Can anyone else replicate the analysis?

If I were doing this, how would I do it more effectively?

Can more information be legitimately extracted from these data?

Is this analysis correctly conducted?

Presentation of the Findings From the Research

What exactly does this presentation tell me?

Does any of this make sense?

Does this fit with what I understood the research and research problem to be all about?

Is this convincing, relevant to the problem, and justified by the analysis?

Is there a better (more effective, more convincing) way to convey the findings?

Interpretation and Conclusions Drawn From the Presentation

Would I or others come to the same conclusions?

Do I disagree (agree) with the interpretation because the results don't argue convincingly or because they disagree (agree) with my own preferences?

Does this interpretation confirm (disconfirm) my own expectations?

What do I know now that I didn't know before?

Have the findings (changed) (improved) (added) anything to my understanding of the problem?

What might these findings suggest for applications?

Who else needs to know about these findings?

Are there any options that I or others like me should pursue based on this research?

As in the problem identification stage, participating constituents can take advantage of each other's unique perspective. In problem identification, they were trying to get a common understanding of the "reality of the problem." In this stage, they have shared each other's perspectives and now can approach interpretations and applications of research in a more concerted and directed manner. Those from a given perspective may prepare interpretations, come up with a new synthesis, grasp certain subtleties, and identify options that have particular credibility and authenticity for their fellow constituents. Given their now greater common experience and learning, they may be able to arrive at more

acceptable options, alternatives, and applications that fit one or more constituencies more broadly than they might achieve independently. Better applications with greater potential value might be identified and workable strategies to achieve broad adoption of research-based applications of the research might be derived were constituents to work in consort in this culminating stage.

This stage is characterized by reflection, interpretation, and synthesis; by identification of implied or direct applications from the research; by identifying conditional factors that can promote or deter adoption; and by accessing appropriate networks and institutions that may be involved in achieving the desired applications. The focus is on how to best communicate, disseminate, and diffuse information, and how to increase the likelihood that the proposed outcome would be used, adopted, and technically integrated into the fabric of the intended recipient of the innovation.

In a constituent involving process, the kinds of activities of the traditional research in this stage would still apply,[5] but there is a more strategic shift because of the continued involvement. The pressing issues they would be concerned with would be where the research can be made to have greatest utility (e.g., who might use the findings, who might like the findings), impact (e.g., numbers of people or professional groups reached), and practical value (e.g., importance for continued funding, contribution to tenure).

In this stage, one would find a revisiting of the applications planning they initially began at the onset of the research. That sketch of possible applications would be re-evaluated as to its making greatest sense. Typical outputs from this stage would be the following:

1. Clearer understanding of the research problem and related problems that may need to be researched.

2. Consensus on the specific knowledge gained through the research and its value among their constituency.

3. Consensus on identified applications that can be achieved given the research findings.

[5] Traditional research activities at this stage would include relating findings to previous literature; clarifying what has been added to knowledge of the phenomena; identifying parameters for how this new knowledge might be applied; preparing appropriate technical reports; and preparing manuscripts for journal, newsletter, and conference presentation.

4. Consensus on strategies to achieve adoption or implementation of the identified applications.

Transfer of Research-Based Applications

This sixth stage is one rarely found in traditional research discussions unless the research had an intended developmental or marketing emphases. Because the researcher is very often considered "objective" and "noninvolved," there is not the anticipation that adaptation or adoption of a scientifically originated application would involve them directly.

Given that the constituents have traveled this far down the research-to-applications road, it takes little convincing to move into the transfer of applications arrived at from the research. Consumers, practitioners, and researchers are uniquely equipped to contribute in a complementary manner to achieving adoption of the following applications: (a) publicity and advocacy, (b) preparation for adoption or utilization, and (c) technical assistance and follow-up.

Publicity and Advocacy. Each (consumer, practitioner, researcher) has access to different networks. Each of these networks may be instrumental in creating awareness of, in achieving support for, or in providing access to needed resources for the new applications. Where the researcher may be a less credible advocate for an application, a consumer or practitioner may be more credible. Where a consumer may create an adversarial response to a demanded change, the practitioner may have the access needed to get the potential change a positive hearing.

Preparation for Adoption or Utilization. No innovation is put into place without having set in place conditions for its adoption. Whether it is "raw enthusiasm" or elimination of the use of another method, these are conditions that require change. What these "conditions" are and how they will have to be changed need to be understood and strategies put into place that make it possible to adopt the innovation. Some conditions are financial, others are traditional, and others are attitudinal. For example, it is not unusual for a "model practice" to fail abysmally when it is tried in a different setting than the laboratory in which it was developed. Too often, the conditions for its transference were not adequately considered with the typical result that the "new practice" was modified into the old way of doing things, rather than replacing the older practice.

Technical Assistance and Follow-up. There appear to be at least four phases through which innovations go that are all critical: (a) enthusiasm for (or against) the innovation, (b) attempts to accommodate the innovation into present operations, (c) testing and discovering problems or flaws in the innovation, and (d) correcting/modifying the found problems of the innovation to meet local conditions or ignoring the identified problems and receiving subsequent rejection of the innovation. Steps (b) through (d) require different knowledge of the innovation and research and represent important teaching and technical assistance efforts.

Again, keeping in mind the unique perspectives that each of the players can bring to the research phase, this sixth stage offers each participant an opportunity to help in bringing about successful adoption of the research-based innovation.

VI. Making Participatory Research Work

The participatory research model is not a panacea and it does not work automatically. Its success takes resources, planning, commitment, respect for differences, and hard work. It requires rethinking how and by whom research is conducted and how constituents can become and be kept involved. Making it work is built upon an understanding of what the constituents can uniquely provide, what must be given up, what will be required of them; it then requires careful attention to making responsible use of what each brings to the research-to-applications processes. It also requires the dual commitments of fiscal and program resources and of staff.

Unique Contributions of the Participants

No two consumers, practitioners, or researchers are alike. The three participants described here have in common a maturity, an informedness, a concern, and a mutual respect. It is upon such traits that a research-to-applications process (that has greater likelihood of a high yield for the investment) can be built. Each constituent is an "expert" within a role. Each has unique knowledge, experiences, skills, values, and needs to achieve rehabilitation solutions. Likewise, they have shared concerns and knowledge that can make it possible for them to work together. These are what, in respective roles, they bring in combination to the rehabilitation problem solving that makes the difference, not whether one person can or cannot possess capacities of all three kinds. The separate and respective value of each role is, in the sum, what each can provide, add, or combine with the other's role to produce a more refined understanding of the problems and the solutions.

Table 5 conveys how individuals from different roles contribute to the research and applications activities. While this is a very elementary (and composite) example, it suggests how constituents within and outside the Center actually complement each other and bring more richness to an effort than might otherwise be available. In particular, this example depicts a researcher who has neither a visible disability nor significant clinical experience but who can list among his/her relevant life experiences the effects of discrimination and a strong record of academic and research accomplishments. Symbiosis and added value begin as consumer and practitioner bring their personal knowledge, passion for change, and know-how to create receptivity for options that make sense in the real world.

Table 5. Example of Constituents Complementing Each Other in the Research Process

Constituent Contributions to Research	
Center Researcher Capacities	**Constituent and Beneficiaries of Center Research**
Strengths	**Consumer**
Technical research skills.	Intense need for real solutions.
History of designing research-applications.	Personal knowledge of disability.
Skills for drawing together information.	Passion.
Objectivity and scientific processes.	Sensitivity to effects of disability.
Desire for knowledge and real solutions.	Sense of real solutions or applications.
Experience with discrimination.	
Deficits	**Practitioner**
Secondary clinical experiences.	Knowledge of variety of applications.
No visible disability.	Experience with disability needs and potential.
	Experience relating to individuals with disability.
	Reality about constraints and barriers.
	Access to resources to achieve implementation.

Functions Fulfilled by Participants

During any and all stages of the research, the constituents might fulfill different functions. The functions presented on Table 6 are ones commonly needed to conceive, carry out, and make use of research findings. The listing is not exhaustive. It is fairly suggestive of different roles the constituents (researcher, consumer, practitioner) might assume in any of the research stages. These are the general functions imbedded throughout Chapter V when discussing the six stages of the research-to-applications process above. Some further examples are also imbedded in the three research-to-applications examples included in Chapter VII. Potential difficulties that might arise by having more people involved in the research process may be partially abated when the constituents are clear about their different functions during the several stages.

Table 6. Functions for Constituents Throughout the Research Process

Constituent Functions	Definitions and Activities Included Under Function
Facilitation	Promotes the interplay and exploration of perceptions in order to achieve a consensus on purpose, direction, or strategy.
Leadership	The result of having achieved consensus among the participants in the research process.
Management	Responsibility, authority, and efficient coordination of the research and/or development activities.
Support	Clerical, recordkeeping, data collection, encoding, transcribing, and other activities necessary to successfully complete the research.
Expertise	Specialized knowledge or capacities to access and/or acquire needed information or to resolve problems resulting from research or application.
Technical	Specialized capacities to achieve or carry out a specific element or procedure in the research or applications plan.
Production	Worker-bee or research assistant who carries out a finite activity in the research or applications plan.
Information	Data or information resource that can only be obtained from the individual as subject in research, member of focus group, or other function.
Analysis	Analytic and synthesis functions to achieve a valid condensation of critical information or data.
Interpretation	Application of prior knowledge and/or the accommodation of reality within the matrix of information produced through the research.
Application	Seeking meaning beyond the specific research, deriving ways that the research provides improvements in the lives of people or constituents affected by the disability.
Monitoring	Quality control methods or techniques applied to ensure the highest degree of validity and replicability of apparent benefits, findings, and/or impacts.
Historian	Contrasts current information against any existing information. A part of the quality control effort, but gives special emphasis to whether research repeats valid techniques or a known faulty practice.
Design	Conceiving methods to sensitively address the research issues or to ensure that alternatives to which the research may identify are likely to have applications beyond the original research conditions.

Table 6. Functions for Constituents Throughout the Research Process

Constituent Functions	Definitions and Activities Included Under Function
Evaluation	Critical and insensitive appraisal of what the research produces. This is the conscience-less critique to discover where the research has and has not yielded anything of value.
Advocacy	Intentional promotion of the research and/or the options and changes that it has yielded. Intent is to create and support those networks and conditions that are likely to ensure widest implementation of an application or research finding or innovation.
Arbitration	Provide an objective means for balancing competing interests in a research plan or in the support of options that may be validly pursued as a result of the research. The function of ensuring fidelity to the intended results from the research or demonstration.

Requirements of the Constituents

Those who are to be affected by the research can be meaningfully involved in rehabilitation research. The "insiders" in the research process have typically been the researchers and those most informed about the value of the research (e.g., funding agencies, other academics). Those included in the research should be the ones who will make use of research: consumer, practitioner, researcher. This will require finding meaningful ways in which the contributions of each can be drawn out to contribute to the quality of the research and to changing practice. If involvement were extended to all three of these players, however, the forms of that involvement can neither be passive nor merely a token gesture. Besides being insensitive and insulting, that involvement would add nothing of value, but would represent a costly nuisance in an already difficult and expensive venture.

As suggested above, there are various functions fulfilled by constituencies at every stage of research. Table 7 presents a planning guide that might be informative as you go about planning your research (or look back at a recent research effort).

Use it to examine the activities that need to be carried out in that research and who would best be able to perform the various functions. Be specific as you identify activities that fit into each function. Who then can perform or do that?

Table 7. A Planning Guide for Involving Constituents Throughout Research

Potential Constituent Functions	Stages in Participatory Research Methodology and Which Constituents May Fulfill the Functions					
	Problem Identification	Research Planning	Conduct Research	Analysis and Reporting	Synthesis and Dissemination	Transfer of Applications
Facilitation						
Leadership						
Management						
Support						
Expertise						
Technical						
Production						
Information						
Analysis						
Interpretation						
Application						
Monitoring						
Historian						
Design						
Evaluation						
Advocacy						
Arbitration						

Is the function something that can be performed equally well by your research staff or by another constituent? Would having some other constituent perform it or share in performance add to (a) increasing the sensitivity of the research, (b) ownership of the research, or (c) plausibility (i.e., credibility) of results that come from the research? As you connect individuals and activities to the stages and functions, you may become quite surprised at how involving your research can be or presently is. I think you will find that it is quite possible to involve constituents more (and as more than respondent to a research instrument).

Evaluating the Meaningfulness of Involvement

Is all or any of this worthwhile? Does the involvement of constituents increase the relevance of the research being conducted? Do we get a broadened ownership for the research? Do we arrive at more valued answers to issues of disability? Is our involvement real, meaningful, or is it simply a shame? Are too many accommodations made to achieve acceptable involvement so that scientific standards have been compromised? Are the applications defined from the research plausible, credible, and adoptable in practice?

These (and many others) are the kinds of questions that must be raised as this methodology is explored and applied. We must be vigilant as we apply these participatory approaches. If they yield no more or no better solutions to rehabilitation issues than do traditional approaches, they may not be worth the time and, potentially, added effort to make them work. If they cannot be effectively used to create solid options that get put into practice, then we should really be re-examining our assumptions about the relevance of this apparently pragmatic approach to change.

We need to devise mechanisms for evaluating the costs and consequences of applying these models, for improving them, and for delimiting where and when they are most effective. Table 8 presents one elementary scheme for examining how a participatory model may have been applied in a given research endeavor. The scheme suggests that value added to the research product should be greater than estimated losses (or compromises) when the model was applied. A variety of dimensions along which quality may be enhanced or losses in quality may originate are suggested. Real value would be defined along three fundamental criteria: Technical and scientific merit, relevance to disability issues, and value of applications and contributions to solving disability issues. Cumulative values added and lost against those criteria would suggest the extent to which a particular constituency and constituency involvement in total was worthwhile.

Reasonable scales or methods can be constructed to obtain the tallies, ratings, and valuing of participants and might be drawn from the participants themselves following the research. Or, assuming that the planning guide suggested in Table 7 were maintained for each individual and constituency throughout the research, those documents could be used by an independent panel of constituents to appraise additions (e.g., of knowledge, sensitivity in design) and losses (e.g., bias, resource cost) in an external evaluation of the participatory process.

Our point here is to suggest that we need to evaluate what we do in this participatory revolution; it is not necessarily a how-to approach. However, as you review how you operate participatory research and have worked to make it work all the way through, you might wish to adapt and try to use Table 8. Do some tallying of the quality of participation by constituents and your staff across a research-to-development enterprise (e.g., you may want to include individual's initials, as well). I would suspect that the cumulative picture will not be as positive as you might hope. Your review of marginal "totals" and the "scattering" of individuals among the multiple dimensions may also suggest how you are actually carrying out a participatory research.

Table 8. A Scheme for Evaluating Constituency Involvement

Properties and Value of Contributions	Contributions of Individual Constituents to Center's Research and Training Projects			Marginal Totals
	Constituent A	Constituent B	Constituent C	
How Value May Be Increased				
Knowledge				
Experience				
Skills				
Values				
Needs				
Special sensitivity				
Other unique attributes				
Cumulative Value Added				
Technical and Scientific				
Relevance				
Applications				
Total Increase in Value				

(Continued on next page)

Table 8. A Scheme for Evaluating Constituency Involvement (continued)

Properties and Value of Contributions	Contributions of Individual Constituents to Center's Research and Training Projects			Marginal Totals
	Constituent A	Constituent B	Constituent C	
Where Value Can Decrease				
Accommodations				
Safeguards and compromises				
Efficiency				
Logistics				
Management				
Staffing supervision				
Public relations				
Resource use				
Bias introduced				
Limits on generalizability				
Scientific merit				
Long-term contribution				
Cumulative Value Lost				
Technical and Scientific				
Relevance				
Applications				
Total Decrease in Value				
Bottom Line = Value Added versus Value Lost (or Costs Added)				

VII. Examples From the Center's Experience

Three examples of research activities where the Center's participatory research model has been applied are presented here. Keeping in mind that the model continues to evolve, the three examples span a number of years. The first example is a research project that started out and was conducted under the current version of the participatory research model. The second example was initiated before and adapted to the model after its first year. The last example actually took place while the Center was working with state agencies in Region V to develop a model for statewide needs assessment. The three examples suggest how the model matured and how it can be applied in research for which real decisions are going to be made. All three examples should also give some idea of how the value of this research improved and/or increased its receptivity and impact.

The examples are presented to demonstrate (a) that multiple constituencies are involved and depend on the rehabilitation issues, (b) that meaningful involvement of constituencies can be achieved in the research, (c) that involvement spans the spectrum of functions, and (d) that real influence and impact can occur in the models. The examples are not presented to either demonstrate a preference for a particular research methodology or to analyze involvement at each stage in the research process. For each example we present an abstract of the problem and results and go on to identify constituencies, the functions they fulfilled, the unique ways the researcher was involved, and the special features that helped tie the method and research process together.

Community-Based Rehabilitation Needs of American Indian People with Disabilities Who Reside on a Reservation

Overview of the Research

Very little research conducted at the national level has application for American Indians on rural reservations. American Indians residing on specific reservations or living in any one of the over 300 Indian nations are communities where language, culture, and traditions distinguish one tribe or nation from another. In particular, these unique features play a determining role in how individual and community needs can be met. Data obtained from the broader society may not be useful for planning and delivering meaningful local community services. Research that would yield methodologies to precisely identify needs and to custom design rehabilitation delivery for rural nations

would be very valuable.

The Oneida people are largely rural-based American Indians living in northeastern Wisconsin. Resources and needs for rehabilitation and other community services have not been documented, though the problems found on their reservation are "similar" to those found on other rural reservations (e.g., significant health problems, drug and alcohol abuse, high school drop-out rates, significant unemployment). In the past couple of years "gaming" has become a prominent industry for the Oneida people. Significant sources of revenue are becoming available to address employment, housing, and health issues on the Oneida reservation. An opportunity was available to participate with the Oneida nation in four areas; this experience may have value to other rural American Indian populations. The four areas included the following:

1. Work with the tribal leaders to develop a needs assessment process that is sensitive to the culture and traditions of the Oneida people;

2. Participate with the Oneida people to define their primary needs for rehabilitation and other community level resources;

3. Participate with the Oneida people in designing strategies or a plan for their acquisition and application of rehabilitation and community services; and

4. Work with and assist in gauging the extent to which their community-based plan has been implemented and has achieved the purposes they intended.

This study was be conducted jointly with the Oneida people between 1993 and 1995. The principal investigator was a staff member of the Center, was of Oneida heritage, and was also pursuing a doctorate in rehabilitation. The focus of the project was on identifying needs through the "cultural conditions" required in working as a guest in the American Indian nation and designing and implementing their plan for resolving needs. A tentative design was submitted through their Health Council and related committees for willingness to participate. After negotiation, permission, and access to cultural, disability, and elders of the Nation was obtained they became involved as the principle constituencies to the project.

The Concerns Report Method was used to identify items for preparing a needs assessment instrument and method for collecting data. Three separate

groups (i.e., elders, service providers, families) worked with the investigator to select items and guide the investigator in establishing a procedure that would be respectful, would likely yield valid data, and would create interest in the research findings. Needs items, where there was high inter-group agreement, became the 23 items on the survey form. The focus of this study was on identifying and determining consensus relative to their needs. In the design, cultural identification and experience with disability through the cultural conditions were independently assessed to determine whether priorities and consensus on needs would be related to those two variables.

One hundred fifty-five individuals from the Oneida Nation completed the Concerns Report. Questionnaires were completed on-site at the health center and at a community meeting over a 5-day period. Elders and members of the three working groups helped create awareness and interest in participating. One critical process-outcome of this study is that the Oneida people of Wisconsin will have information that they can use for community planning. A profile of priority needs has been prepared that appears independent of cultural identification or disability.

The findings will now be presented and reviewed in a series of Town Hall Meetings on the reservation and then formally submitted to the Nation's Budget and Legislative Committee summarizing research findings, constituent reactions and conclusions, and their recommendations on further actions by the people to begin any further programming. The subsequent stage may involve staff, as guests of the American Indian nation, who would help them design and implement their plans for resolving needs through culturally appropriate channels.

Constituencies

Oneida Legislative and Budget Committee
Family members of persons with disabilities
Individuals with disabilities
Elders and registered voters within the Oneida Nation
Public agencies providing health and social services

Constituent Functions

Perspectives representatives
Review, select items
Define content of needs assessment
Support, promote data collection

Review and interpret findings
Design implementation schemes
Proponents for defining services

Researcher Functions

Co-source for promoting identified needs
Advocate for community-based rehabilitation
Collaborator and interpreter in groups
Synthesizer and listener to the people
Prepared instrumentation and the process
Administered questionnaire to respondents
Analysis and summary of findings
Translation of data, interpretation of reviews, and needs
Public spokesperson for value of needs data in decision making
Suggested options and potential applications of findings
Resource persons to Nation and to other resources to establish programs

Special Features That Made It Work

Creating awareness and potential value
Patient and conscientious review throughout the approval cycle
Principal investigator member of Nation, though inactive
Co-principal investigator research and statistical expertise
Relationships and building of trust throughout 15 months
Testing for credibility at each stage
Clarifying the potential value of products from research
"Token" payments for participation
Cultural responsiveness in all meetings and interactions
Culturally paced
External constituency review committee

Development of the Vocational Assessment Protocol for Planning and Case Management With Persons With Traumatic Brain Injuries

Overview of the Research

This study investigates the use of the Vocational Assessment Protocol with persons with traumatic brain injury. The goal of this initiative is to produce a

protocol including processes and instrumentation that can be adapted by community-based programs that are developing programs for persons with traumatic brain injuries. Several data collection instruments are being examined that serve as the core for developing data management systems. Through field testing the Vocational Assessment Protocol, a practical approach to profiling critical information relevant to vocational rehabilitation of persons with a traumatic brain injury is being developed.

While the project was technically conducted over 48 months, it really came about from a long line of research conducted by the University of Wisconsin-Stout Rehabilitation Research and Training Center on needs of people with traumatic brain injuries (see Thomas, Menz, & McAlees, 1993). Areas identified for this assessment protocol were developed through a consensus conference conducted under the auspices of the Atlanta Think Tank in 1988, two national conferences sponsored by the Center on community-based employment of persons with brain injury in 1989 and 1992, a continuing clinical advisory committee to the research, and a supported employment project (Thomas & Menz, 1990). Collectively, this instrument has been placed in a format for documentation and summation of critical elements related to return to work following a significant traumatic brain injury. The Vocational Assessment Protocol was originally field-tested and adapted based upon statistical analysis and constituent review. Presently the Vocational Assessment Protocol is in its final experimental format and is being field-tested to establish reliability and validity of all instruments and the processes suggested in the protocols at 20 sites nationally.

As vocational rehabilitation programs have begun to accumulate experience in working with persons with traumatic brain injury, it has become apparent that the nature of the sequelae of this disability is substantially different from that of other disabilities (Levin, Benton, & Grossman, 1982). Approaches to case management and employment development have been based upon methods used successfully with persons diagnosed as mentally retarded or who have a serious and persistent mental illness (Lezak, 1987). These types of approaches may be similar in some respects, such as the fact that lifelong services or service access are often necessary (Wehman & Kreutzer, 1990) and that a cadre of services are often required to maintain the person in an integrated community setting (Wehman, Kreutzer, Sale, West, Morton, & Diambra, 1989).

The needs of the person with a traumatic brain injury though, are substantially different in many other respects and, therefore, demand a different type of service delivery. One of the primary differences between this population and other disability groups is the fact that these individuals may overtly appear

more independent and vocational competent than experience will bear out (Lezak, 1987). Furthermore, they often maintain their pre-injury self-concept, even though they may be considerably different since their injury (Thomas & Menz, 1990). The cognitive, personality, and behavioral deficits that are a direct result of cognitive dysfunction are often difficult to diagnose and recognize by lay persons (Thomas & Menz, 1990), especially when problem behaviors and skill deficits are inconsistently exhibited.

This project has developed a method of assessment to assist in the case management for persons with traumatic brain injury who are likely to need sustained rehabilitation services for an indeterminate period of time. This case management approach is based upon an information integration system, the Vocational Assessment Protocol is a natural outcome that evolves from the suggested protocol for assessment. This project proceeded in three phases, each of which was contingent upon the former stage for developing materials, accessing a subject pool, and establishing rehabilitation programs as data collection sources.

The goal is to provide a method for conducting a comprehensive vocational assessment that provides a solid basis of information for use in providing long-term case management for persons who have sustained a traumatic brain injury that has resulted in a severe and persistent disability. The model will incorporate the practices that have proven to be necessary and effective in (a) case managing persons having long-term medical, physical and psychological needs; (b) sustaining persons in various types of supported, protected, sheltered, and competitive employment situations; and (c) maintaining the least restrictive and most appropriate independent living arrangement.

A two-day training program for vocational evaluators and rehabilitation counselors and case managers was convened at Midwest Regional Head Injury Center for Rehabilitation and Prevention in Chicago in July of 1992. All individuals attending the training program were trained in the use of the Vocational Assessment Protocol. Each site was required to collect complete information on at least two consecutive referrals of persons with traumatic brain injury to their facility. The two-day training program provided general training in vocational evaluation procedures for persons with traumatic brain injury, introduced the various data collection devices, and trained each participant in the use of the instruments and procedures. Over the course of the following 12 months, persons referred to their program for brain injury services were profiled on these forms. The persons profiled in this research included persons from Region V, including Wisconsin, Minnesota, Michigan, Illinois, Indiana, and

Ohio. The site staff collecting the data were vocational rehabilitation specialists who also had the responsibility of conducting vocational assessments and appraisals on their clients.

On the basis of a reliability analysis and factor analysis, the Vocational Assessment Protocol was revised into its final experimental version. This version was reformatted and sequenced based upon the input from participating research sites, advisory sources from the Center and the Regional Center on Traumatic Brain Injury, and experiences or problems encountered with it in constructing workable rehabilitation plans. In this form it represents a structured approach to profiling important information from persons with brain trauma injuries who are being assessed for community-based employment.

The Protocol now consists of nine individual Profiles, each with its own set of directions and format for collecting and documenting important information and a Program Path and Evaluation Strategy Form that is primarily for research purposes. The Structural Summary report is chiefly for clinical and reporting purposes. When the instruments are used in combination, they constitute a protocol or a process rather than simply a battery of instruments. The Vocational Assessment Protocol was **not** designed to represent a stand alone system of vocational evaluation, but rather was intended for use in conjunction with other evaluation strategies and approaches. It will provide new programs with the rudimentary information needed to perform a comprehensive assessment if all directions are closely followed. The Vocational Assessment Protocol was designed for use with existing vocational evaluation tools and approaches without drastically changing the nature of the user's system of assessment.

The outcomes of this study have been numerous to this point. Twenty-three sites have been trained in the use of the Vocational Assessment Protocol, and nine individual profiles and two ancillary reporting formats have been developed for use with persons with brain injury undergoing vocational assessment. The process for using this information in case management is being developed into a monograph that will be completed by the end of this project period. A journal article describing the initial findings of the pilot testing of the Vocational Assessment Protocol is in process, and another article that details the broader cross validation with all 20 sites is planned when all data have been analyzed.

Constituencies

Service delivery personnel (rehabilitation, medical, psychological)
Individuals with traumatic brain injury

Advocates and family members
Payers for services
Vocational rehabilitation counselors

Constituent Functions

Identify service delivery problems
Identify public policy issues
Identify relevant published and unpublished sources
Co-authored proposals and papers from studies
Co-sponsored national forums and conferences to solicit broadest input
Conducted priority setting activities to define information contained in protocol
Piloted initial components
Reviewed and provided critiques of protocol process
Defined practical strategies
Served as mentors for new users
Collected validation and satisfaction data
Assisted in designing appropriate training and technical assistance
Presented experiences and research findings

Researcher Functions

Clinical knowledge and vocational evaluation expertise
Summarized information for public reviews and guidance
Co-principal investigator was practicing clinician with a vision
Co-principal investigator had technical skills in instrument design and validation
Conducted and advised multiple master's theses
Systematically collected input from constituencies and applied in redesign
Conducted model demonstration service delivery project
Authored and collaborated in book publishing
Conducted site visits, consultation to staff and consumers at pilot sites
Conducted training of original pilot site staff
Debriefed training with all pilot site staff
Co-trained pilot-validation sites
Designed instrumentation within protocol
Conducted statistical analysis to synthesize and redesign protocol
Promoted clinical acceptance of effort and product

Special Features That Made It Work

Dealt with and contributed to defining issues of national concern
National and advocate concerns drove effort
Modest payment of clinical advisors
Clinical and consumer experience was origin of the project
Co-funding and multi-year efforts across projects
Training and involvement of practitioners throughout
Involvement of individuals with disabilities throughout
Multiple constituency review committees
Clinical advisory committee
Support and attention from national leaders in clinical and advocacy
Relatively small sample sizes
Competition for sites to participate in protocol validation
Preparation and linking of sites with mentors
Monthly monitoring of participating sites via conference calls
Sites distributed at 20 locations around country
Multiple informed consents and assurances of consumer protection

Development of a State Rehabilitation Plan for Ohio

Overview of the Research

The Rehabilitation Act requires that each state prepare and submit an annual State Plan that defines whom the state rehabilitation will provide services to, how it has established its priorities, what its programs are to address priority needs, the extent and how it will provide a state-match to its federal allocation, and how it will responsibly administer and spend its federal allocation. To do this, each state is required to conduct a statewide assessment of needs by populations and programs identified in the Rehabilitation Act. In the late 1980s the Center was working with state agencies in Region V to develop processes that could be used in common by the states. The product of that Study Group's efforts was an assessment-planning-implementation-evaluation model with many of the features that are now part of the participatory model described in this monograph.

Between 1988 and 1989, the Ohio Rehabilitation Commission elected to make use of the assessment model and guidelines the Study Group prepared. As part of their process, the Center was asked to participate as facilitator and technical resource to the Commission's in-house evaluation and planning staff. On three separate occasions, the author went to Ohio and in 3-day periods helped the

agency with the general structure of the evaluation-to-state plan development process. The state agency identified its constituencies as consumers, advocates, private sector service providers, and rehabilitation agency staff. These constituencies and the individuals representing them remained pretty much intact throughout the entire cycle.

The intent of the combined effort was to prepare a state plan that reflected assessed needs and the interpretive actions those needs suggested to and through the agency's constituents. The agency would conduct the formal and technical aspects of the needs assessment and work with constituents to set parameters for the assessment and to develop recommendations for the state plan after the assessment was conducted. The technical assistance the Center provided was both facilitation and technical soundings and occurred coincident with the three major stages in the study. First, constituents were convened for a two day period to identify goals and topics to be included in an assessment, to explore their ideas about methods for sampling and data collection, and to cement their involvement and commitment to making the assessment work. This resulted in these constituents writing items and searching the state to find people who would respond to a statewide survey.

Second, after a preliminary instrument and data collection method was put in place, constituents were again convened and worked with to review content and settle on the instrumentation, how students with disabilities would person an 800-number, and what kinds of analyses they might want to have available for review. In the third phase, facilitation shifted to helping constituents compress statistical information, identify key recommendations in program and population areas, and formulate specific recommendations that might be incorporated in the plan. The usual safeguards were included throughout, and the technical details were actually carried out by state agency staff.

Sensitivity to consumer needs had payoff: Information on progress and results of the survey were shared in agency newsletters, students were available to complete questionnaires by phone over an 800-number, public presentations were made on why the effort was being conducted, public meetings solicited comments on a proposed state plan that incorporated constituent recommendations. These payoffs were (a) in an unusually high rate of return for a one-pass survey, (b) needs information that was valued by decision makers and constituents, and (c) credible recommendations incorporated in the state plan. Also, (d) constituents were invested in the entire assessment-plan development cycle and (e) the agency could feel confident that the plan was in keeping with consumer expectations.

Constituencies

Individuals and family of individuals with disabilities
Advocates for access and service effectiveness
Service providers used by State Agency
Program planners for state rehabilitation program
Rehabilitation counselors
State Legislature

Constituency Functions

Set objectives for statewide assessment
Guided selection of parameters for statewide sampling design
Identified methods to reach special populations
Participated in instrument development and review
Carried out telephone data collection
Interpreted assessment data
Formulated recommendations
Encouraged public responses to recommendations and state plan

Researcher Functions

Developed the overall process
Facilitated constituency input and consensus building
Prepared alternate sampling designs
Devised data collection methods
Trained telephone data collectors
Coordinated and monitored data collection
Prepared data for consumption and review
Drafted and integrated input for recommendations
Drafted relating elements of state plan

Special Features That Made it Work

Maintained same constituency panel throughout
Multi-section questionnaire relevant to specific targeted disabilities
Sampling targeted to geographic parts of state
Used facilitator to elicit and synthesize panel input
Involved students with disabilities as interns for interviews, data collection, and analysis
800-number for reporting needs

Plan recommendations clearly
Public hearings on assessment and on state plan
Relatively high response rate
Small internal staff
All panel and facilitator time voluntary

VIII. Promises and Potential Pitfalls

In the previous sections of this paper we have tried to convey the idea and potential that may be realized should we consciously engage all of our partners in the rehabilitation research process. We have offered a conceptual model, grounded in the scientific process with a simple addition relating to applications, and have tried through example to engage the reader's thinking about how this idea of constituent involvement might work profitably within the rehabilitation enterprise.

As you re-examine our ideas — and you recognize how they continue to evolve through our examples — I wish to leave you with some rather personal observations about what we might be able to achieve through research and the impression of what research is all about. Were we to fully achieve this partnering or constituent involvement or integration of perspectives suggested above, perhaps we might recognize a different product from our research enterprises. As I have come to understand research in rehabilitation, we are faced with two alternatives — one that too often expresses what our constituents see taking place through rehabilitation research, and one that we desire and can probably achieve were our models-protocols-methodologies more involving and respectful of what constituent involvement adds to rehabilitation research:

> **Research Defined by Traditional Roles.** Traditional research can be likened to an equilateral table in an angular room to which access and participation are available only to key-holders producing sharply defined ideas ... Research is conducted at a table around which decision makers sit and work to arrive at answers to problems they know to be important.
>
> **Research Respecting Constituent Involvement**. This research can be likened to a round table in a round room producing well rounded ideas ... Research is conducted at a table around which sit all the players who have a stake in the life-game being played out among them.

Efficacy of Constituent Involving Research

In prior sections we have presented to the reader advantages for increased constituent involvement and strategies to optimize these benefits. We have also tried to convey areas where vigilance may be required to ensure that the effort is neither a sham for constituents nor a dubious example of scientifically relevant research. In the most immediate section preceding this one, we stressed a need to attend to known merits and limitations of this model. Planning and evaluation

schemes were suggested as ways to systematically examine whether and how well the process is truly involving and yielding greater benefits.

The unresolved issues fundamental to establishing efficacy of this kind of model appear to center around procedural issues (i.e., specific problems or issues involved in conducting respectable research), administrative or institutional issues (i.e., manageability of research under such models), and ethical issues (i.e., how results are postured and defended in the non-research arenas).

Research Procedural Issues.[6] The conduct of research involves some systematizing and well established conventions as to how research can be efficiently conducted. While many of these "rules" can be adapted with minor and not so minor consequences to the scientific rigor of research, both the vigilance we attend to in research procedures and some of our favored practices (e.g., using very structured questionnaires) will be replaced (e.g., with transcribed interviews using limited prompts and requiring very conscious recording and encoding of interviewee statements). Areas of change include:

Value or relevance of the issue as understood by the group. Whether the issues or research questions arrived at by a constituent group are worth the expected investment in research. To what degree is this constituent group on target with the mainstream of concerns?

Representativeness of perspectives and of issues selected. Whether the individuals included are truly representative of the constituent, their point of view or position, and whether they are in a position to discern issues of a non-parochial concern. Will these people be able to detect and aid in defining non-trivial problems in need of substantial solutions?

Assumptive base of group. Whether the constituent group comes to the

[6] This discussion is based in part on our observation of how participatory research is unfolding and issues raised by Center Directors, Research Directors, and Training Directors at the 1992 Annual Meeting of the National Association of Rehabilitation Research and Training Centers. The Annual Meeting was held in Washington, DC between March 17 and 19, 1992. The panel provided "A Critical Analysis of RTC Readiness and Progress in Implementing PAR." In addition to Dr. William Graves, Director of the National Institute on Disability and Rehabilitation Research, the panel was composed of Rud Turnbull, Families, Beach Family Center; Samuel Stover, Historical-Medical, University of Alabama Medical Center on Spinal Cord Injury; Jack Genskow, Consumer; Donald Olson, Training, Rehabilitation Institute of Chicago; Rick Offner, Rural, University of Montana; Fredrick Menz, Vocational, University of Wisconsin-Stout (Chair).

research endeavor with a set of assumptions that constrain or direct inquiry to predetermined outcomes. Assumptions about cause, rightness, and valuing can shape the research endeavor to foregone or biased conclusions. To what extent will the assumptions the group brings to the research shape findings?

Reliability of findings. Whether the qualitative and more informal approaches to research are followed; where are the benchmarks or guidelines to permit independent observation and replication? A fundamental criterion in all research is that the steps and conclusions drawn can be either replicated or arrived at through an open presentation of evidence available to the original researcher.

Validity versus apparent truth. Whether safeguards have been introduced to assure not only replicability of findings but that conclusions and recommendations drawn are fully in keeping with the quality, reliability, and extent of evidence supportive to the conclusions. Were the data or evidence subjected to the appropriate and rigorous analytic principles (i.e., interpretation of qualitative or quantitative data are carefully and legitimately carried out)?

Technological and mechanical. Whether the procedure used to determine constituents, select representatives, and to fully exploit the input and participation of all representatives was carried out in a predictable and logical manner. Whether real consideration for the value and contribution of volunteers was respected. Whether dollars and other forms of compensation or accommodations were recognized, planned for, provided for in budgets, and attended to throughout the endeavor.

Truth and popular appeal. Whether the topic, method, and activities of the research are directed toward revealing what is or toward supporting popular conceptions of disability and rehabilitation. To what extent does this research pander to popular images or a particular ideology?

Administrative and Institutional Issues. These issues are ones of reality that are encountered by entities trying to conduct meaningful research under normal institutional rules (e.g., employment rules and finite resources (such as grant dollars).

Resource acquisition and allocation. Capacity to plan and budget capital and human resources where constituent involvement drives timelines,

accomplishment, and the extent of constituent participation (and added costs) in any of the research-to-application stages. This can be a significant issue when conducting research against a level-funded project or with predetermined end-points.

Staffing. The issues of paid-unpaid, professional and non-professional classifications in most institutions raises havoc. In universities, union protected, and civil service settings, very certain protections from exploitation have been established. First, to what extent are these volunteer constituents replacing work done for wages? Second, to what extent are volunteers being exploited or abused through their "contributions" to the research? Third, to what extent should volunteers be held accountable for completion of the project?

Balance within budget. The greater the numbers of constituents participating in the research, the more likely is there to be unusual costs incurred for travel (e.g., attendant travel), participation (e.g., hiring of interpreters), and preparation of products in alternate formats (e.g., costs to produce a few captioned videotapes). While some items may be anticipated in the budgeting process, and therefore allowed as expenditures in the project's budget, not all of them can be either anticipated or anticipated in exact dollars.

Affirmative action (e.g., hiring based on disability, volunteerism, exploitation). Whether reverse discrimination is practiced in search for underrepresented constituents and/or employees for the project. Whether and to what degree the activities of the project will be hampered by recruitment and retention provisions under affirmative action guidelines.

Organizational accountability. As increased latitude is granted to constituents in the research effort, at what point does responsibility for progress and research outcomes become dependent on the consensus or responsiveness of the constituents? To what extent does responsibility and control move away from the project?

Costs encountered to implement safeguards. Whenever there are suspicions that our procedures will not yield reliable data or valid conclusions, we must introduce safeguards that check for or control potential invalidation of the research. These safeguards add cost and use resources. Such safeguards require collecting added information (e.g., to confirm soft measures) or to install methods to monitor input,

progress, and quality. Each instance adds new activities (e.g., mini-studies of the inter-rater reliability of consumer, practitioner ratings; training consumers in conducting valid environmental scans). What are such added fiscal and procedural costs? Are they in reality beyond the pale of expected rigor?

Ethical and Values Issues. These issues resolve, in particular, around what we do with findings from research. In a rather global sense, these issues deal with how well we stick to what the research has actually told us and whether what we do with the results are logical extensions. One might liken this to acts of integrity in relation to new knowledge.

Rightness. Extent to which the process yielded true findings and those true findings are clearly communicated to and understood by constituents.

Responsibility. Balance between producing findings that are acceptable in keeping with scientific standards and presenting findings that are valued by constituencies. Given the level of investment, there is always an implicit expectation that the research will provide useful solutions or alternatives. Research does not, however, provide those guarantees. Likewise, in the cautious fashion of researchers, useful findings are often overlooked that appear in the shadow of the larger findings. Value added at the conclusion of the research is not always the same as value intended at the initiation of research. Sometimes, the perspectives of constituents rightly, as well as wrongly, detect highly valuable applications.

Relevance. Extent to which combined research processes yields real and lasting answers to the important questions that the research was supposed to address. To what extent do the findings provide answers to substantial or trivial or parochial questions? Are the answers and procedures used to achieve those answers in keeping with the present issues?

Restrictiveness. Potential to produce an intentionally restricted perspective of a problem and narrowly applicable findings. Bias can be introduced through the assumptions or values presented by constituents and subsequently shape the research design and conclusions from the research data.

Protection of human subjects. Subjects become more visible as participants. To what extent does becoming known, due to being

participants in the process, present untoward repercussions for the individual? With increased constituent involvement, where do rights of disclosure and protection from subsequent penalties apply?

Assumptive base. Beliefs and expectations for a preferred world-view and how they influence issue identification, acceptability of options, inquiry, and interpretation of findings. To what extent do such assumptions not only shape the research, the evidence gathered, or the manner in which the evidence is drawn together and interpreted but also shape the interpretation and application of evidence to practice with other persons? To what extent has one's perspectives on what should be done as a result of the research been borne through an absence of what might be legitimately concluded from the research.

Propositions

In a previous section I suggested that what we are engaged in in rehabilitation research is very much like adult learning. What we do in adult learning is less about establishing foundations of knowledge and much more about shaping and engaging the intellectual and experiential bases of lives to pursue and acquire something phenomenally and personally enriching — in effect, the derivation and accumulation of what can be. I believe that in many respects, our research endeavors are about working through and either resolving what reality is (i.e., what really works) or identifying what reality could be for people and our social institutions (i.e., discovery of alternatives). In this vein, and by way of closing, I propose the following about what it is that research — and research in rehabilitation — is all about:

Research is a collection of processes.

Research deals with events, conditions, and issues as they are presently known.

Research is interdependent with environment, yet will be shaped by the environment in which it is applied.

Research processes are applied in order to understand and to control other environments, events, objects, and processes.

Research is a creative and productive enterprise.

Research has, as its product, something we know or know more about than we did before.

Research is a way of getting a better look at the world, environment, events, processes, and actions.

Research is, therefore, among the techniques to influence change or introduce solutions to real-world problems.

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